National Library of Canada
Acquisitions and Bibliographic Services Branch
395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale du Canada
Direction des acquisitions et des services bibliographiques
395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

Canada

UNIVERSITY OF ALBERTA

IMMIGRANT WOMEN, DISABILITY, AND CULTURE

BY

LAN WAI CHAN-MARPLES ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION.

IN

ANTHROPOLOGY AND EDUCATION

DEPARTMENT OF EDUCATIONAL FOUNDATIONS

EDMONTON, ALBERTA

FALL 1993

National Library
of Canada

Acquisitions and
Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale
du Canada

Direction des acquisitions et
des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-315-88344-8

Canada

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: LAN WAI CHAN-MARPLES

TITLE OF THESIS: IMMIGRANT WOMEN, DISABILITY, AND CULTURE

DEGREE: MASTER OF EDUCATION

YEAR THIS DEGREE GRANTED: 1993

Permission is hereby granted to the University of Alberta Library to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves all other publication and other rights in association with the copyright in the thesis, and except as hereinbefore provided neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatever without the author's prior written permission.

Lan Chan-Marples

10423 - 86 Avenue
Edmonton, Alberta
Canada
T6E 2M4

DATE: 8 October 1993

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled IMMIGRANT WOMEN, DISABILITY, AND CULTURE submitted by LAN WAI CHAN-MARPLES in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION in ANTHROPOLOGY AND EDUCATION.

Dr. A.D. Fisher (supervisor)

Dr. S.H. Toh

Dr. D. Bai

DATE: 14 September 1993

ABSTRACT

Literature on immigrant minority women has increased in the last few years, but little has been written on those who have disabled children. The study is a review and interpretation of current research-based literature on immigrant women and disability, written from various fields and theoretical perspectives, with a special emphasis on studies which focus on ethnic minority immigrant mothers of disabled children. Using primarily North American literature, some key issues in the everyday experiences of these women as immigrant women, as visible minority women, and as mothers of a disabled child were identified.

The study also discusses the women's underuse of mainstream health resources and social service agencies. Ethnic minority parents with handicapped children also underuse special programs. Their use of health services has been limited by lack of information, host-language skills, bicultural and bilingual staff, culturally sensitive and appropriate professional practices regarding disability.

Thirdly, this study highlights some of the racial, classist, handicappist, and sexist issues faced by immigrant minority women in their daily lives. It explores the thinking of feminist scholars to explain how the labels immigrant, women, and ethnic racial minority have been constructed from the women's relationships with the dominant community. From these perspectives, it also looks at the relationships between immigrant minority women and the health care system. In all these areas, the myriad of ideological and structural contradictions, hardships, and barriers made women's adjustment to a new culture a difficult task. Yet, they themselves have been regarded by the dominant population as the source of their own problems. As women living between two cultures (country-of-origin and host-country), the dilemmas face by immigrant women have been shown to be manifold.

Furthermore, the conclusion identifies areas which require further scholarly investigations. New research should investigate how the powerful factors of gender, religion, class, ethnicity, patriarchy shape

the experiences of women with disabled children. Researchers must note both the differences and similarities of the immigrant mothers' pre- and post-migration backgrounds and experiences. These women must be permitted to identify their own issues and concerns when caring for a disabled child at home.

TABLE OF CONTENTS

Acknowledgements

CHAPTER **Page**

I. INTRODUCTION 1

- 1.1 The Purpose of the Study 10
- 1.2 Considerations and Limitations 16
- 1.3 Conclusion 22

II. VISBILITY AND INVISIBILITY: THE EXPERIENCES OF VISIBLE MINORITY AND IMMIGRANT WOMEN IN CANADA 24

- 2.1 Re-conceptualizing Visible Minority and Immigrant Women 29

III. VISIBILITY AND HEALTH: IMMIGRANT WOMEN AND HEALTH CARE EXPERIENCES 45

- 3.1 Immigrants and Health Services: An Overview of User Status 52
- 3.2 Diversity/Difference Among Ethnic Minorities: A New View of Health Care Behaviour 58
- 3.3 Immigrant Women and Mainstream Health Care: A Visible Dilemma? 69

IV. ON BEING A VISIBLE MINORITY IMMIGRANT MOTHER WITH A DISABLED CHILD 92

- 4.1 Immigrant Mothers' Reactions to a Child's Disability 101
- 4.2 Immigrant Mothers' Perception of the Child's Disability and its Cause 113
- 4.3 Support Networks and Utilization Patterns 130
- 4.4 Caring Mothers and Mothers as Caregivers 150

V. GENERAL DISCUSSION AND CONCLUSIONS 157

5.1. Research Strategies with Immigrants, Immigrant Women, and Racial Minority Parents of Disabled Children 172
5.2 Concluding Remarks 177

BIBLIOGRAPHY 183

LIST OF FIGURES

2.1 Immigrant Mothers' Various Dimensions 27

Acknowledgements

The initial idea for this study arose while I was caring for my severely disabled daughter a few years ago. Interest in the situation and experiences of immigrant minority women predated her birth, a result of my own immigrant family background. Shortly after her death, a chance conversation with Dr. Carl Urion (my neighbour at the time) about an idea of mine to bring the two parts of my life together - disability and ethnic-racial minority - and make a general private study out of it led to his immediate encouragement to pursue this as an academic one. Shortly after this, I entered the Master of Education program under the guidance of Dr. Urion in the Department of Educational Foundations. I would like thank Dr. Urion for his endless support and enthusiasm throughout the program. I deeply appreciate the knowledge he has instilled in me. I am sorry that his health curtailed his role as supervisor in the last year. Nevertheless, I have gained a true friend and mentor (and his special family) and I hope that this remains unchanged for many years to come.

I would also like to give special thanks to Dr. A. D. Fisher, who took me under his already crowded wing from Dr. Urion. While I was sad about leaving Dr. Urion, I was extremely grateful that I was to complete the crucial part of the program, the writing of the thesis, with Dr. Fisher. There are no words to express my appreciation for the supervision he has given me in the formation of the thesis. His invaluable insights, support, and editorial skills made it possible for me to complete this project. In the changing of supervisor I have gained another mentor and friend. I deeply appreciate that he has agreed to continue to supervise me in the doctoral program.

Thirdly, I wish to thank the other committee members, Drs. David Bai and Toh Swee-Hin, for their additional valuable comments on the thesis and for agreeing to sit on the examining committee.

Over a year ago I approached an immigrant women's organization about my research and eventually got to know a tremendous group of women who are staff members there, and immigrant women themselves. Besides their wholehearted support of my project, I was

also given the opportunity to assist the social worker in creating a support group for immigrant mothers with disabled children. It was the first support group in the city for this group of women. My relationships with the organization (Changing Together - A Centre for Immigrant Women) has evolved from outside researcher to ESL teacher to board member. I have a deep respect for the hard work and dedication of the staff there in meeting the many needs of immigrant women. They do so under limited funding support and shortage of staff. I have also met some wonderful women who come to the centre. However, it is the immigrant minority mothers of disabled children whom I have come to know through the support group, that I would like to acknowledge. It is they who make my project worthwhile and necessary.

Finally, I wish to give an extra-special thanks to my husband, David, for being there with me throughout. His patience, support, and cooking have kept me going, in spirit and in body. I would like to express my appreciation for his editorial skills and feedback; and for being such a wonderful parent with the children, for the packed school lunches, and for the tasteful curries and other meals. I am grateful to my parents, Jim and Mee, and in-laws, Ella and Neville, for their understanding, love, and help during the difficult years following the birth of our handicapped child, and with the other children as well. My two sons, Carlton and Keelan, deserve a special award for putting up with my grouchiness and my many hours in front of the computer. I wish to give memory to our daughter, Nicole, who had left us with a special feeling in our hearts.

CHAPTER I

INTRODUCTION

Research is scant on immigrant and visible minority mothers caring for children with disabilities at home in Canada. The idea of examining Canadian published materials to see what current scholars have to say about visible minority immigrant women with handicapped children was problematic from the start. The wealth of information hoped for - from previous empirical works on disability and ethnic and racial minorities women as a subject matter - did not materialize. In fact, compared to the abundance of data on mother-disabled child dyad studies in general, research on racial minority immigrant mothers and children with special needs in health, education, social work, rehabilitation and other related areas are disappointing. The United States have been somewhat more productive in terms of research into this particular group of minority mothers and their disabled children. Although it was not possible to examine all the literature related to the present study - because of time constraints and inaccessibility - the author was able to locate some current information about immigrant and visible minority women, parents of disabled children, and community health services and programs for immigrants and people with disabilities.

However, the paucity of Canadian literature forced a heavy reliance on non-Canadian papers (both biographical and analytical) on ethnic minority and/or immigrant parents with disabled children for this study. These sources, which were predominantly American, provide a sense of what minority immigrant mothers with children who have disabilities are experiencing in Canada. However, inferences from non-Canadian studies could only be made at the most general level. It would be misleading to go beyond this since this would give the false impression that the experiences of this particular group of mothers are alike, regardless of the country to which they have emigrated. Yet the social, political, and cultural history of the country of destination regarding immigration, minorities, disabled people, and health care differed in various ways or degrees from country to country. The experiences of minority immigrant mothers of disabled children are shaped by these factors in their new country as well as by their particular personal history such as ethnic origin, social class status, education, religious beliefs, and other factors. Also, the available evidence does not yet permit a comprehensive review of all areas pertaining to this special group of women.

Because of these problems, the scope of the present study was changed somewhat. The initial intention was to review available and recent Canadian empirical studies in the area of visible minority immigrant women with disabled children from an anthropological perspective. However, the lack of Canadian and anthropological research in this area soon prompted a different line of inquiry: why have visible minority immigrant mothers with disabled children received so little attention from professionals and researchers? The answer to the question is complex.

By shifting the study's line of inquiry it was possible to include research from various disciplines and countries which specifically looked at ethnic minority immigrant women and ethnic and/or immigrant parents with disabled children. In the latter case, American and British scholars in social work, psychology, rehabilitation, special education, and sociology fields were the most frequent. This is most evident throughout this study, but more obvious in Chapter VI. Despite the lack of Canadian content in this area, the information from non-Canadian studies did provide me with some insights into the lives of these mothers in Canada. They also show how important it is to conduct our own investigation with such a group of women with disabled children. With the former, I was able to base much of the general discussion on the immigrant experience and health and health care problems of ethnic minority women on findings from Canadian immigrant studies. In these areas there is a small increase of research by Canadian scholars, particularly with immigrant women as their primary focus (see especially Chapters II and III).

My interest lies in the situation and experiences of immigrant ethnic minority women in most advanced capitalist societies such as

Canada, the United States, Britain, and Australia. More particularly in the manner which ethnic minority mothers caring for physically or developmentally impaired children negotiate their everyday experiences in both their private and public domains in order to meet the general (like any normal child) and special particular (like any disabled child) developmental needs of their handicapped children. What role do their various social characteristics: immigrant, ethnic minority, women, mothers, informal caregivers, cultural keepers and transmitters, and, for many, wage-earners, play in these women's daily social life? More specifically, to what extent do these social variables affect their self-esteem, their relationships with their disabled children and other family members, their patterns of obtaining and maintaining appropriate and necessary services for the health and well-being of their disabled children, their interaction with helping professionals, and their use of available support networks?

However, comprehending immigrant women's perceptions of and attitudes toward the immigrant and/or health situations in which they find themselves and the practical activities of daily life (i.e., housework and childcare) provides only half the picture (see Anderson, 1987; Meleis, 1991; Ng and Ramirez, 1981; Ralston, 1988; Szekely, 1990). Immigant women's experience is continually being shaped by their everyday interaction with the larger society, and thus research into their lives should begin with women's experience from women's standpoint.

Future researchers on the lifestyle of visible minority and immigrant mothers with disabled children might seriously consider this line of inquiry. As a group, non-white immigrant women are different from white immigrant and Canadian white and non-white women. As mothers with disabled children, they are different from other mothers with non-disabled children. As individuals, they have different racial or ethnic, political, religious, social class and other attributes. The different characteristics of the children's handicapping conditions (i.e., degree of severity and type of disabilities) render the experience of immigrant mothers with disabled children unique. They require a method of inquiry that takes into account the differences, while acknowledging the similarities of the immigrant mothers' situations. When we create a space for women to identify their own issues and concerns in the actualities of their everyday worlds, we can have a closer sense of what it means for immigrant mothers to care for a disabled child at home.

With reference to the modern health care system in Canada, I was curious about its (1) effectiveness and (2) degree of ethnic consideration for these culturally and socially diverse groups of women. Social and health care service agencies have been criticized frequently for their lack of sensitivity to ethnicity in both policy and practice within their facilities and services. An example is health clinics, which open and close at the same time as general businesses. Immigrant women in low wage, high pressure, and easily filled jobs cannot afford to leave during the day for a child's medical or therapeutic treatments (the facilities are open only during the day time) because of potential loss of wages or fear of losing the job. This is slowly changing today, due to the great efforts of social advocacy groups made up of parents, women, professionals and public individuals, who have pushed for a broader health care system which covers a wide range of users or consumers and their various dimensions of work and social life.

These were the thoughts which influenced the framework of the present study. Other ideas have emerged over its course. Primarily, the thesis is a review and interpretation of current research-based literature on disability, written from various fields and theoretical perspectives, with a special emphasis on studies which focus on ethnic minority women. It is hoped that a bibliographical review may provide some insights into the key issues surrounding the everyday experiences of these women. The hardships, frustration, fear, challenges, and other factors of being an immigrant woman from a visible minority or being a parent to a severely disabled child have been expounded on and explored in these other works. From them, one can begin to understand the complex situations: as immigrant women, as visible minority women, and as mothers of a disabled child. If their problems can be identified, then health care and social services can be directed to meet the particular needs of this group of immigrant mothers and disabled children. One direction is that their needs be met in a much more culturally appropriate and sensitive manner than in the past, not in a ritualistic ethnic manner but with a real understanding of each woman's ethnic cultural as well as her personal background. At present there is a general lack of interest in this group of visible minority women within visible minority women, which unfortunately reflects incomprehension of their needs and the realities of caring for a child with a disability. In this, greater research efforts would provide the vital information to those involved in all levels of health care, social services, and educational institutions for persons with disabilities and their families.

Whatever difficulties other women are experiencing, they will be heightened or doubled for the visible minority group under study. Some of the comments made by some Indo-Canadian women to Anderson (1987) corroborate this view. These women often felt the racial prejudice of white Canadians. Because of these feelings of discrimination, non-white women generally considered white Canadians as unfriendly and unapproachable (p. 432). Likewise, such views, according to Anderson, have also been extended to Canadian health professionals, who in turn often reinforced the perceptions of non-white women by their racist behaviour. For example, in Struser's study (cited in Anderson) of the birth experiences of Indo-Canadian women in hospitals, the women described instances of perceived discrimination by hospital nurses (p. 433). They maintained that Canadian women from the mainstream culture received preferential treatment from the nurses. For immigrant and racial minority mothers with disabled children, the implication from both Struser's and Anderson's studies is that they would face even greater discrimination with health professionals and white Canadians in general because of the double stigma of visibility or being different and bearing a disabled child.

At present, the needs of the women are not being met appropriately, if at all, because they have few opportunities to define their needs about their own experience and concerns with raising a child with a disability. The everyday life of such a woman and mother can be perceived as more complex when compared to white, Anglophone or Francophone, Canadian mothers with nondisabled and disabled children and visible minority and immigrant women with nondisabled children. Beside the usual difficulties of immigration, such as adjusting to a new culture, lifestyle, language, and separation from family and friends, a visible minority woman must also confront racial, religious, gender, class and/or cultural discrimination by the larger society. The myriad of everyday problems and difficulties encountered by visible minority immigrant women has been well documented. Many women believe they experience more stress and hardships, and as a result are poorer in health than before they came to Canada (see Anderson, 1987).

According to an American Asian study by Chan (1979), the birth of a child with disability has the potential to intensify an already negative and stressful personal and familial situation because it can worsen already harsh living conditions, menial jobs or underemployment, and/or shortage of family resources in the host country. Now, the immigrant family must adjust and adapt to a new culture and lifestyle as well as with a disabled culture and lifestyle. As mothers are generally the primary caregivers of disabled children, this puts pressure on mothers to learn quickly about the special clinical, therapeutic, educational, and social services and programs in order to ensure and maintain their children's quality of life (Mary, 1986). In this immigrant mothers with disabled children are no different from other mothers with disabled children whether they live in Canada, the United States, or Britain; however, as many studies have shown, the difficulties were mainly with the delivery and staffing of special services and programs. For example, the absence or near absence of bilingual and bicultural specialists or paraprofessionals working in community health, clinical, educational, intervention and rehabilitation institutions has been viewed as a major barrier for culturally diverse immigrant women who speak little or no English.

The view that the service needs of disabled children and their immigrant families are similar to those of mainstream families with disabled children is reflected in service delivered and has been much criticized by North American and British scholars. Instead of developing culturally relevant programs and services to address the particular needs of the immigrant population, various organizations simply extend their existing systems and approaches developed to serve white, middle-class families. For example, some immigrant mothers found that the health service centers tended to be located in areas inaccessible by bus (see Chan, 1979). Secondly, it is not always easy to take a disabled child on public transport, especially if it is a long ride and inappropriate social behaviour is a problem related to the child's disability. Meeting treatment appointments for many of the immigrant women who do not drive or own a car then became an added strain. Such underlying attitudinal and systemic barriers within culturally insensitive or irrelevant programs and organizations frequently lead to negative experiences on the part of the visible minority mothers. The majority of immigrant women with nondisabled children will experience similar culturally insensitive health care and social services. However, they would not experience this with the added dimension of disability.

Another dimension of the present study is to discuss the women's experiences with existing health services and social agencies. It will examine current Canadian and American findings on service delivery to ethnic minority and immigrant populations in general. A common observation by helping professionals about ethnic minorities living in North America is their tendency to underuse mainstream mental health resources and social service agenices (Chan, 1979; Christensen, 1987). Various reasons have been suggested for this: (1) the model minority concept (the ability of ethnic minorities (e.g., Chinese and other Asians) to overcome hardships and gain acceptance with few mental health problems) (Christensen, 1987:189); (2) the resources to resolve their own problems within ethnic communities and within the family circle (Chan, 1979:13); (3) discrepancy between culturally determined values and attitudes toward and definition of health and illness and Western definition and attitudes (e.g., feelings of shame, fear, and guilt associated with mental illness) (Anderson, 1987; Chan, 1979; Christensen, 1987); (4) an indigeneous/traditional medical care system established within one's ethnic community (Hessler, Nolan, Ogbru, and New, 1978); (5) attitudinal and systemic barriers underlying mainstream service delivery; and (6) a specific ethnic group's perception of the functions of certain services, i.e., many Chinese people consider social services as a source of help only for concrete, practical problems (e.g., housing) and not with psychosocial problems (Christensen, 1987).

The need for Canadian professionals in social and medical organizations and society at large to recognize and address the possible health problems with these mothers became evident when examining the broad spectrum of literature and talking with some visible minority and immigrant mothers of children who are handicapped. Their emotional, mental, and physical health and well-being are at risk because of the double distresses that many of these immigrant women experience in their everyday lives: the migration experience and the caring for a disabled child. Both society and professionals must begin to respond to the needs of this particular group of immigrant mothers. One way is to evaluate current policies and practices to ensure that they reflect the realities of these women. Another is to promote research initiatives and their continuation in order that there is a wealth of knowledge in this area.

Not only is the immigrant women's health at risk because of the stresses of adapting to a new life in Canada with an imperfect child, but most of them are at risk as potential victims of abuse because of the child and the associated shame, embarrassment, and extra financial burden and responsibilities brought on the family. Low income immigrant parents are more likely to feel the financial strain of a handicapped child. Besides the above-normal cost of care for a disabled child, there is also the possible loss of the mother's income. This occurs if the disabled child requires constant care and alternatives are beyond the family's resources or difficult to access.

The author was first made aware of abuse in the lives of the immigrant women when she became involved with racial minority immigrant mothers with disabled children and ethnic community workers. Further investigation revealed that violence against immigrant and racial minority/women of colour has been a recent concern in Canada (Shin, 1992). Wife assault and sexual assault are realities for immigrant women and women of colour at grassroots level. More research is needed in this area, as with many other areas concerning immigrant women raising children who are disabled.

Immigrant women are not the only ones vulnerable to abuse. Their disabled children are also at risk. Westcott (1991) reported that the problem of the abuse of disabled children has not received the full attention it deserves. Only recently have American professionals working in the child abuse field begun to address this problem, yet, research into the abuse of disabled children has been conducted for the last three decades. These additional difficulties facing visible minority women will heighten what may already be a crisis situation because of immigration and disability; or more accurately, because of the dominant society's response to visible minority and immigrant women and disability. Furthermore, it is suggested here that the vulnerability of these visible minority immigrant women to, for example, racial and class discrimination and wife and social abuse is increased by the addition of a disabled family member.

This is not meant to be a definitive study. The underlying themes of the study are as follows: (1) in support of new thinking in the social sciences, to highlight the diversity of ethnic minority women's attitudes, beliefs, and values of childrearing, motherhood, selfhood, and even disability, as opposed to the assumed cultural homogeneity noted in studies; (2) to advocate a more culture and gender sensitive model of health care, especially in regard to ethnic immigrant mothers (or fathers) with disabled children; (3) to support the demand by other scholars for greater public and governmental attention to ethnic and/or racial minority women and their relationship with disability; and (4) to address some of the problems which have arisen, or may arise, for this group of parents. The ethnic minority mothers, regardless of their racial or cultural background, cannot be treated as if they were uniform, homogeneous, and undifferentiated, because "the assumption of cultural homogeneity is an unwarranted stereotype which can produce misleading results, particularly when studying ethnicity. . ." (Hessler et al., 1978).

Secondly, women's lives are dynamic and ever changing, and so is the environment in which they live. The cultural life has changed over the years, and evolved into a peculiar form, which is a mixture or a synthesis of the old experiences and knowledge and the new, and not a hybrid; nor is it an imitation of the dominant culture (Mukherjee, 1990). Any texts on ethnic minority and immigrant mothers caring for children with disabilities must be both synchronic and dychronic, otherwise they cannot depict the true reality of the women.

1.1 The Purpose of the Study

The study opens up a long neglected debate on ethnic minority immigrant mothers caring for disabled infants and young children in the home in Canada. All the issues under scrutiny here have important implications for the well-being of this group of Canadians[1] because their personal lives have been left out of the social and political agenda of state social and health care policies, and disability and mainstream feminist movements. They have been rendered invisible in the social and health care policies because in comparison to the general disabled population, the size of ethnic minority people with disabilities is extremely small. Consequently, little consideration has been given to the appropriateness of existing policies and services in both health care and social sectors for minority families and their disabled children. Bureaucratic and economic considerations play important roles in the generalization of services to all handicapped people and families caring for members with disabilities. This kind of universal treatment is problematic for both immigrant as well as non-immigrant disabled people and their families since no two disabled persons or families are the same, albeit they may be similar. Specifics and generalization need to be incorporated within every grand design to serve people with disabilities and their families more effectively.

---

[1] When asked what it means to be ethnic and what ethnicity has to do with being an ethnic or visible minority immigrant woman, Bannerji's (cited in Mukherjee, 1990) response was: "It means that we are not considered to be Canadians. We are 'immigrant women'. This is a prominent category. They don't even talk about us as Canadians" (p. 146). She added that when we talk about immigrant women we don't mean Germans or Finns and Swedes or the French but those whom the state decided to be *ethnic* such as Third World people and even some southern Europeans. Even visible minority women who may be Canadian-born or -raised found that in their everyday life they were often perceived as immigrants (Szekely, 1990:127). I agree with Szekely and Bannerji that immigrant women should not be made different because of social processes which have portrayed them as racially and ethnically inferior (Szekely, p. 127) or as a way of managing and subsuming (cited in Murkerjee, p. 146) visible minority women and will like to begin with great pleasure by talking about them as Canadians. However, for the purpose of the present study I will retain the terms immigrant and ethnic minority to refer to those women who have emigrated from Third World countries and southern Europe. Much of what will be said in the study will also concern visible minority women born in Canada because visible minorities have traditionally been viewed by the general public as an immigrant class. Seldom were they evaluated on the basis that they are individuals with different identities and social history.

One reason for the few disabled is the undesirability of persons with disabilities, and the notion of preferred immigrants in Canadian immigration policy. It is thought they will be potential life-long clients of the social, educational, and health care services in Canada; in other words, a burden on the new society. Thus, the number of disabled people entering Canada has been reduced through immigration policies. Although this policy was revised in 1992, the supposedly more tolerant version is still discriminatory in regard to sense of class and disability. Disabled people are allowed to enter provided they or their families can demonstrate their financial ability to support them(selves) and not be reliant on existing social services. This means that only those disabled people from the upper socioeconomic classes are allowed to emigrate.

For many years, women of colour in Canada have been rendered invisible by mainstream feminist groups because the latter have been battling the problems of patriarchy, oppression, and exploitation of women from a white, middle-class, and highly educated standpoint. From their racial and class positions of prestige white, middle-class feminists have spoken for every woman. However, the story they tell is a monotone one in both sound and colour because it has none of the vibrant colours and tones of class, race, social, political, educational, religious, cultural, and personal differences. Mainstream feminists have persistently failed to include perspectives other than their own. As a result, feminist women of colour have begun to mobilize to set up their own feminist agenda which takes into account those factors that mainstream feminists have left out such as imperialism, colonialism, and immigration.

White, middle-class, feminist groups must recognize and allow for differences among women. For example, immigrant women are oppressed and exploited in different ways from Canadian women and among themselves. At the same time, all are oppressed as women. Differences in education, religious affiliation, economic class, racial background, and others between immigrant women reflect different forms of oppression and exploitation. "We cannot simply say that all immigrant women have a common lot - or a common enemy" (Szekely, 1990:129). What they do have in common is being immigrants and women. However, the actualities of their everyday world differ from each other.

Secondly, mainstream feminist and disability movements have ignored the plight of disabled women. Again, some of these women are advocating their inclusion in both movements and others have formed their own particular movements. Like immigrant minority women, women with disabilities have been represented by nondisabled privileged women. Hence, the needs of both these groups of women have been covered by general feminist and/or disability canopies. However, the general women's movement has taken up the causes of non-white and non-middle-class women (Szekely, 1990) and disabled women. In fact, both mainstream movements are becoming increasingly sensitive to those who they have previously excluded or included. Perhaps the recognition that, despite similar broad issues of gender discrimination, exploitation, and oppression in the labour force, education, family, and other social instititutions, women do not come from homogeneous social backgrounds and share similar experiences. However, it will take time and energy to change some of the embedded ideologies before harmony can be achieved between the various kinds of women in Canadian society.

It is not, however, the purpose here to examine the medical characteristics of childhood disability or the disabled children themselves. There is already a corpus of literature on these topics. For this study, the term disability refers to "irreversible physical damage which interferes with [the] physical, mental and/or intellectural function [of an individual];" a simple and straightforward definition borrowed from Mardiros (1989:55). A person with a disability resulting from biological, environmental, or physical factors requires specialized intervention or modification of the environment in order to function effectively. However, a person is handicapped when the person "encounters cultural, physical or social barriers preventing his or her access to systems available to other citizens. Thus modifications to an environment of a physical or social nature may reduce the handicap but not the disability" (as defined by UN World Programme of Action 1986, see Brown, 1991:1). Brown (1991) points out that disability and handicap are not felicitous terms. However, they serve the purpose of this present study.

Also, dominating recent social science and feminist research is the nascent theoretical perspective that the terms immigrant women, visible minority women, and disabled children/adults refer not so much to individual attributes, legal status, or physiological characteristics, but rather to social attributes which are constructed and defined in the social relationships between these individuals and other members of Canadian society (e.g., non-immigrant, white, and nondisabled members) (see Buscaglia, 1983; Ralston, 1988; Szekely, 1990. See also the references given below). When disability is understood as socially constructed we can begin to understand the strong influences of the social, economic and political structures on disabled people's daily lives which made them handicapped as well as disabled. Buscaglia (1983) devoted an entire chapter in his book, *The Disabled and Their Parents,* to stress the point that a handicap is made, not born (the chapter's title). He states that people with disabilities do not find their actual disability the biggest detriment to full participation in society, rather it is attitudinal and physical constraints created by nondisabled people in society which turn disability into a handicap. In Hahn's view (1987), people's attitudes toward disability and disabled people are much more powerful in restricting opportunities than physical barriers. Based on the presumptuous image that handicapped people are biologically inferior, others determine how people with a particular disability should or should not behave, the kind of social roles they can or cannot fulfill, their sexual capabilities, their personal characteristics (e.g., weak, dependent, passive), etc. (see Begum, 1992; Buscaglia, 1983; Dossa, 1990; Funk, 1987; Hahn, 1987; Moyes, 1981; Westermeyer, 1979).

> They treat them as children unable to take decisions or responsibilities. They assume they have no sexual desires. Worst of all, they regard them as patients who really ought to be getting better even though their disability is not curable. Disabled people are forced to accept society's definition of their future. Such attitudes are found worldwide and often they cause a bigger problem to the disabled than the disability itself (Moyes, 1981:7).

Similarly, immigrant women are not born but made, by immigration policies and through social relations. Visible minority women do not find their dark complexion or other physical features unusual until white Canadians see them as different, and often behave in ways to show it. These kinds of behaviour were often felt by Anderson's (1987) study subjects, the Indo-Canadian women. This led the author to offer this observation:

> One could argue that non-white women's experiences are shaped by the history of imperialism and oppression, and are not only the result of their immigrant status. Instead, these experiences have to be understood in terms of their status as non-white women from a Third World nation. So, not only must non-white immigrant women contend with ideologies about women's roles, but they must also contend with stereotypes that are entrenched within the mainstream culture, which determine the ways in which they are perceived (p. 433).

Ralston (1988) puts in a nutshell the current developing theory pertaining to the study of immigrant women in Canada:

> In this conceptual framework, gender, ethnicity, race, and class are also understood as social attributes which are defined and constructed in the historical and ongoing processes of social relationships, not as individual attributes. Gender refers to a principle of social organization which is constructed and reproduced in the historical and cultural processes of socialization, not to a physiological (or psychological) attribute. Ethnicity and race also refer to social constructions, not to individual membership in a descent group. Class is defined in terms of the cultural and ideological context as well as the relationship to production (p. 65).

Class, gender, ethnicity, and race are the variables which are closely tied to the everyday world of immigrant and visible minority women. Underlying them are dominant ideologies, such as notions of femininity and sexuality in the home and in the workplace, which determine the specific positions of these women within various social and economic institutions and their subjective experiences in those positions.

Literature on disability and families is also beginning to advance the notion of 'difference' between the situations and experiences of individuals with disabilities and their families. Findings show that factors such as personal/family resources (e.g., financial, support network), type and degree of severity of the disability, past experiences with disability, marital stability, and other factors play a crucial role in shaping individual experiences (Beckman-Bell, 1980).

In essence, the present study is an attempt to understand how ethnic minority immigrant mothers caring for children with a myriad of disabilities negotiate their every day experiences in both their private and public domains in order to meet the general (as any normal child) and special (as any disabled child) developmental needs of the children. Given their various social, and even political, characteristics: immigrant, ethnic minority, woman, mother, informal caregiver, cultural keeper and transmitter, and, for many, wage-earner, what role do these elements play in the women's social life? More specifically, what effect do they have on the mothers' self-esteem, their relationships with their disabled children and other family members, their patterns of obtaining and maintaining appropriate and necessary services for the health and well-being of their disabled children, and their interaction with helping services professionals? My purpose is to argue for the inclusion of these particular groups in future disability, ethnicity, immigrant, feminist, health care and community social services research, movements, and all levels of policy development and practices. They too have needs, aspirations, concerns, and wishes like other women living in a disability situation. They too have insights and knowledge about childhood disability and being mothers to disabled children.

1.2 Considerations and Limitations

The survey of the literature was limited to the last fifteen years based on three factors: (1) a noticeable increase of publications during this time on minority women of colour by women sharing the same characteristics; (2) an in-depth review of older studies, and in a number of instances even of the same studies, by new scholars to provide background information for their own particular piece of work; (3) the greater interest in resource utilization and support networks of families with disabled children in this period (Mary, 1986). Concurrently, there is a similar increase of interest in the study of resource utilization and the support networks of immigrant and visible minority families, especially with recent immigrants in North America and Britain. There is a growing awareness that the state of the family's resources (e.g., financial) and the availability of formal and informal support networks are crucial factors for a positive or negative immigration experience.

White, middle- or upper-class women have been well-studied. Histori-cally, the mother-child relationship within the family was considered to be the first social dyad. It was thought that mothers have a significant influence on the behavior and personality of the child. For this reason the mother-child relationship was highly studied (Buscaglia, 1983:65). Today, emphasis is on the interactions of the entire family rather than on mother-child relationships. Both in theory and practice, the whole family concept has become the most accepted model in many fields working with families.

Canadian-born women of visible minority ancestry are excluded from the present study. As with visible minority immigrant mothers of disabled children, at present there is little research literature on native-born visible minority mothers of disabled children. It would be interesting and challenging for future scholars to examine the experiences of the latter as well as the former group of women. However, the lived experiences of native-born visible minority women with disabled children could not be assumed to be the same as foreign born visible minority women for various reasons. First, the personal and social histories of the two categories of women were not the same: the history of one group was constructed within Canada whereas that of the other was formed outside of Canada, in the immigrant women's own country-of-origin (Szekely, 1990). A popular Western notion is that an immigrant is a person without a history, rather than a person with a history that is different from Canadian-born from both dominant and nondominant cultures.

Second, the migration experience coupled with backhome culture beliefs and ideologies about disability, would assuredly influence the way an immigrant visible minority woman perceives her situation and disability. It is unlikely Canadian-born racial minority women would experience the difficulties that have been associated with the process of immigration: separation from family members and social support networks, isolation from people, changing gender roles and responsibilities, lack of the dominant culture's language skills, a drastic shift in lifestyles, and many other problems documented by researchers (see Anderson, 1987; Asian Women United of California, 1989; Christensen, 1987; Meleis, 1991; Moraga and Anzaldua (Eds.), 1983; Ng and Ramirez, 1981; Nyakabwa and Harvey, 1990; Ralston, 1988; Szekely, 1990; Thomas, 1988; Yee, 1987). Visible minority Canadian mothers may be more accepting of the disabled child due to their awareness and support of Canada's changing attitudes towards people with disabilities. In the countries from which the majority of immigrant women recently came, attitudes and perceptions of disabled people are still harshly discriminatory, and such individuals are frequently abandoned or neglected. In the past few decades in Canada, parents of handicapped children, handicapped people, and various government organizations have actively lobbied for the integration of disabled people within their own communities rather than segregation in large institutions or hospitals. The movement towards deinstitutionalization has also meant that parents are expected by the health care agencies to take on more of the care responsibilities for a disabled family member at home. Overall, the special services and programs for children and adults with disabilities in Canada can be considered to be the most enlightened and advanced in the world. There are vast differences in the quality and types of health services and education for children with special needs in developed nations such as Canada, the United States, and Western Europe and other advanced capitalist and less advanced societies (e.g., Africa, China, Eastern Europe, India, Japan, South America, and Southeast Asia).

These are some of the differences which make the two groups of women unlike in many respects. But they share similar experiences in their everyday life with persistent discriminatory attitudes toward racial minorities by members of the dominant culture. These women are subjected to various forms of unequal social relationships between themselves and the dominant group, and it is largely in this that their experiences are similar. Previous research findings have shown that Canadian-born visible minority women have frequently been identified and subsequently treated by members of Canadian society as immigrant women (Szekely, 1990). Ralston (1988) observed in her article that immigrant women is a term which is rarely used to denote women who come to Canada from the Commonwealth, Northern Europe, or the United States: white, anglophone, Christian, Western women (p. 64). In other words, the dominant group has defined, on the basis of selected physical and cultural features considered most different from their own, the memberships of dominant and subordinate groups.

In these papers, the term immigrant women generally applied to women who were born outside of Canada to distinguish them from the Canadian-born women. Even after they have become Canadian citizens and lived in Canada for many years, there are certain societal attitudes and institutional barriers which emerge, occasionally, to remind them of who they really are. I call these occasions 'situational reminders.' During these times they are prompted by the dominant group to remember who they are lest they try to get above themselves in the vertically arranged multi-ethnic and class levels of Canadian society. This is a truer depiction of Canada and its people than the horizontal picture politicians and multicultural advocates try to sell to Canadians. For these reasons, it is not easy for an immigrant and ethnic minority woman to shed her labels 'immigrant' and 'ethnic minority' and join the rank of the majority as simply Canadian.

Ethnic minority immigrant women who come from an upper social class stratum in their homeland are even more conscious of their immigrant and minority positions in the host country. They have to abandon their old class system and face a new one in their adopted country. This frequently means downward class mobility for them. It is the frequent contradictions between old social status (upper class) and new social status (lower class) that immigrant women found the hardest to overcome. Although their upper class standing in their home land is well understood and recognized within ethnocultural communities, it is ignored in the wider Canadian society. If one of these women has a child with a disability she will need to seek health care and special educational services and programs for the child. She will be confronted with health care staff who may treat her in the new status to which Canadians commonly assume all immigrants and ethnic minority belong (wholesale ethnic group stereotypying), rather than the social class in which this woman was born in the old country. She may be distressed by the disrespect shown herself and her child by health care staff members when once she was highly respected and remains highly respected within her ethnocultural community. The variable class is a complicated one for immigrant ethnic minorities to come to terms with, particularly in the face of downward class mobility. Besides the problem of race and ethnic inequality in the cultural and social structures of the Canaidan society the majority of immigrant and nonimmigrant ethnic and racial minority people also experience the problem of class inequality.

I have initially used the term immigrant women to refer to women who are relatively new to Canada (between 1-5 years residence) and disabled children as those who were born in Canada during these years. It was my hope at the beginning of my research to find information which fits these traits. The intent was to understand the impact of immigration and the birth of a disabled child on women who have recently emigrated from Third World or South European countries and who are raising very young children with obvious disabilities. However, no single Canadian study was found which met or come close to the study's parameters. Three American studies came the closest.

Among the families of 58 clients of Asian ancestry who were registered with the Childrens Hospital of Los Angeles Regional Center which were sampled by Chan (1979), approximately three-quarters of the parents he had interviewed were foreign-born and the remaining one-quarter were born in the U.S (Table 6.3, p. 55). The mean length of residence in the U.S. for the foreign-born parents was eight years. Their average age was 46.6 years. In terms of the ages of the 58 clients with developmental disabilities, they were grouped thus: 12 were 0-5 years, 17 were 6-12 years, 9 were 13-19 years, 18 were 20-45 years, and 2 were over 46 years (Table 6.2, p. 53). In the study, the disabled clients were commonly referred to as 'children' by the author, despite the fact that almost one-third of the clients were of adult age (18 and over). Unless he used specific examples it was difficult to extract information which pertains only to families with disabled children who were in the 0-5 years range.

Another study was Mardiros' (1989) of Mexican American parents with severely physically disabled children. Here, the disabled children sampled ranged from 2-26 years and the mean age was 8.2 years (Table 1, p.56). However, Mardiros did not mention the birth origin of the parents, and for those born outside the U.S. their length of residence in this country. From the comments made by some of the parents, it is clear that they were Mexican-born. For example, a number of parents spoke about handicapped children like their own whom they had seen in Mexico (pp. 64-65). One thing she did indicate was the age range of the parents at the time of the study. They range between 21-55 years of age (mean 37) (p. 56).

The developmentally disabled White, Black, and Hispanic children in Mary's (1986) study ranged in age from five months and 5.7 years with the mean age of 3.3 years (p. 79). Out of the 60 mothers interviewed, 45 indicated their primary spoken language was English and fifteen spoke Spanish as their primary language. The ages of the mothers at the time of interview were between 21 and 50 years (mean 31). There was no indication of the origin of the mothers so it was not possible to determine if some of the mothers, especially the monolingual Spanish speaking mothers, had immigrated to the U.S. or not. Although the age group of the disabled children and the gender of all and the ethnicity of some of the parents meet my criteria, the characteristic immigrant is of an uncertain fit. It is difficult to tell which mothers were immigrants and which were native-born.

On the other hand, we could all be considered immigrants in one way or another judging from the ways we are sometimes treated. People of colour, even fourth or fifth generation American-born blacks, may find that others behave towards them as if they were immigrants because they look and speak differently. In the latter case, it may be a matter of regional accents, such as southern versus northern American speech, but a black person with a southern accent may find herself being treated in the same way as black immigrants from Africa, the Caribbeans, and the West Indies - as a foreigner and as an immigrant.

One of the current topics of research is the experience of immigrant women within the Canadian health care system. Previous research has shown that these women frequently experience distress and emotional upset from the difficulties they encounter in a new country (Anderson, 1987). Many immigrant women, particularly those migrating from rural areas in nonWestern countries to urban centers in Western nations, experience more health problems than in their native country. Unfortunately, these works contain little information about ethnic minority and immigrant mothers of disabled children. Not surprisingly, the few accessible articles and dissertations on or about ethnic minority and/or immigrant women with disabilities or parenting children with disabilities are predominantly by ethnic minority and/or immigrant scholars (e.g., Begum 1992; Chan 1979; Gupta 1990).

Women from these same groups have been involved in mother-child studies, such as the ever-popular traditional topic, fertility and childbearing functions. Unfortunately for immigrant women, such studies have concentrated on their reproductive ability (Meleis, 1991). As a result, Meleis argues, data on other aspects of immigrant women's lives are poor. Little research (or community health care service attention) has been directed to immigrant women: with adolescent children, who are old, or caring for elderly parents or relatives. Added to Meleis's list of immigrant women topics ignored is the present specific parameter of immigrant mothers with children with a variety of handicapping disorders. Present and future professionals and researchers involved in health care, special education, community service, women's groups, immigrant agencies, and specific ethnic organizations could do much to promote an understanding of the various health and non-health related concerns and issues confronting immigrant women's daily lived experiences in the new host society.

1.3 Conclusion

In conclusion, ethnic minority women with disabled children experience multiple oppression and subordination on account of gender (being female), motherhood (reproduction), and birth (being associated with a particular ethnic group). All three themes represent complex power relations and ideologies. The result is that women, disabled people, and minority culture groups are in relatively low status and have devalued social roles. One need not guess the strata into which the particular subjects of this study fall. As Goffman (1963) pointed out, when individuals find themselves in a shared stigma category, they will have "a tendency to come together into small social groups whose members all derive from the category" (p. 23). Although Gupta (1990) may agree with Goffman on this, she has also discovered that although the mainstream parent support network she had joined was

> totally white and their concerns very Eurocentric . . . it was less racist than a lot of selfhelp groups can be. The interesting thing about the process of having a disabled child is that it breaks down preconceptions about the norm. Women having to face the prejudices of society about disability become far more sympathetic to other 'deviations' from the norm - Black people, single parents, etc. (p. 104).

When we are immersed in our particular cause for selected groups of women or individuals with disabilities, we should not lose sight of the fact that the multitude of problems affecting ethnic minority women or people with disabilities overlap cultures. Yet, this does not necessarily imply they are identical. These people may have hopes, differences, anxieties, fears and emotions like other women and nondisabled people (see Begum, 1992:81), but despite the similarities, there is a diversity among them that is informed by the personal characteristics (e.g., socioeconomic status, education, race, sex, religion, and others) that are part of their life history.

CHAPTER II

VISIBILITY AND INVISIBILITY: THE EXPERIENCES OF VISIBLE MINORITY AND IMMIGRANT WOMEN IN CANADA

This chapter will outline the current status of research on visible minority and immigrant women in Canada. Information, mainly sociological and feminist, on their experiences in Canada has increased in recent years. The literature to date has largely focused on the complex relations between race, class, culture, and gender in the immigrant women's everyday experience. Discrimination (e.g., racial and employment) against immigrants and gender oppression of immigrant women has acutely affected the lives of all immigrant women in Canada. Some scholars (see for example Anderson, 1987; Chow, 1989; Dua, 1992; Mukherjee, 1990; Ng and Ramirez, 1981; Nyakabwa and Harvey; Ralston, 1988; Szekely, 1990) maintain that discrimination and oppression of non-white/visible minority immigrant women should not be assumed to be the same as for non-white immigrant men and white immigrant women and men. They do agree that we need to hear the voices of the women themselves about their particular experiences in Canada. A second shared view is the need for continuous research efforts on visible minority and immigrant women. The more we know and understand of their experiences, the fewer cultural misunderstandings and racist stereotypes will exist (Begum, 1992:70; the author is speaking for both visible minority women and handicapped women). Outside of fundamental commonalities - being an immigrant and being a woman - immigrant women are not a common lot (Szekely, 1990:129). Class status, education, religion, culture, and race are some of the obvious differences between them.

Mainstream (white, middle-class) Canadian feminist theory is also under criticism in the current literature. There is a general objection by new scholars to the way socialist feminists have attached visible minority women to their pre-existing tenets and approaches to gender oppression and discrimination. The assumption of a universal patriarchal form of social relations has failed to identify the specificity of gender oppression for visible minority women and how it is created and maintained in the family and in society (Dua, 1992:6). In addition, racial and class factors and the reproduction of gender ideology in Canada are often not taken into consideration (Dua, 1992:7). Much of this is a reflection of the mainstream feminist movement which has been primarily of a certain socioeconomic class of women of a particular colour: white, middle-class, and well-educated. These feminists have focused mainly on changing the inequality and patriarchy of western capitalist societies to better the lives of all women. However, they assume that all women from different racial backgrounds and class levels in these countries have the same views as themselves. Moreover, if capitalist patriarchy (defined in feminist theory as the interrelationship between capitalist relations of production and social relations of reproduction) is the basis of gender oppression for immigrant minority women as well as non-immigrant white women in advanced capitalist societies, how is this oppression and exploitation of women created, Szekely (1990:133) asks?

Racism and sexism have serious implications for the subjective experiences of visible minority immigrant women. Baureiss (1987) says bluntly:

> Racism is the most blatant form of discrimination . . . "[M]odern racism refers to the political use of racist ideologies to justify group discrimination through exclusion, subordination, exploitation, and genocide". "Although Canadians have sought to deny the fact, racism in Canada has always been a serious problem" (p. 16).

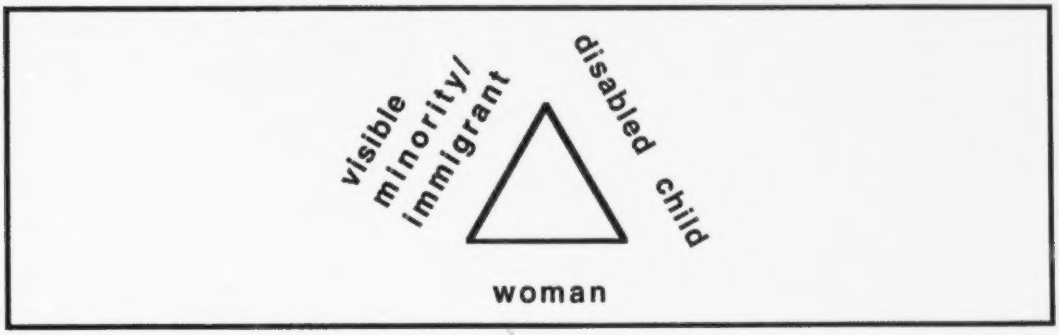
Ethnic minority people are discriminated against on the basis of their physical, cultural, and/or behavioural attributes. And the most blatant forms of discrimination against ethnic minorities are deliberate discriminatory immigration and government policies and situational discrimination found in employment, education and other social institutions which may be unintentional (Baureiss, 1987:16).

Visible minority is used to describe women who are visibly different in skin colour, language, dress, customs, work activities from members of the dominant culture in Canada (Ralston, 1988:64). The term immigrant women is often used synonymously with visible minority women by members of the dominant culture to refer to women who have migrated from countries with non-white populations. Although a legal term designating the status of an individual in Canada, immigrant women is frequently taken to mean visible minority women. Perhaps the significant increase of immigrant women coming from South Asia and other non-white countries since the 1960s over those from Europe is the reason behind this confused cross application of terms.

In addition, immigrant women has also been used to describe both women who may be Canadian citizens and have lived in Canada for more than twenty years and native-born women (Ralston, 1988; Szekely, 1990; Thomas, 1988). It is seldom applied to white, anglophone, Christian, Western women who have entered Canada from the Commonwealth, Northern Europe, or the United States (Ralston, 1988:64). The South Asian immigrant women in Ralston's study observed that being easily identified puts visible minority women at a disadvantage over minority immigrant women who are not. The latter women are not identified as immigrants until they begin talking.

Our brief discussion in this study is selective. The strategy is to focus on the relevant dimensions: visible minority immigrant mothers with disabled children. These mothers straddle three positions and experiences: (1) immigrant women, (2) visible minority women, and (3) mothers of disabled children (see Figure 2.1 on p. 26). In essence, when we speak of oppression or discrimination of this special group of women, we are in actuality speaking of multiple oppression. Racism, sexism, classism, and handicappism need to be taken into account.

Figure 2.1 Immigrant Mothers' Various Dimensions



All four terms are created out of the interrelationship between two sets of people: the white and the non-white, men and women, middle- and upper-class and lower-class, non-disabled and disabled. They are categories created from the attitudes of a particular group towards another group. For example, the notion of white superiority and white colonizers give white Canadians the legitimacy to devalue those who are non-white. In other words, racism, sexism, handicappism, and classism are systemic structures of power which define the parameters of the day to day lives of certain ethnic minority, immigrant, disabled people, poor, women, and other marginalized groups.

Racial discrimination is one of the many issues faced by these visible minority immigrant mothers. As females, the women will encounter institutional barriers (e.g., labour force, education, health care, social services) because of the sexist attitudes of advanced capitalist societies towards women. And thirdly, being mothers of handicapped children they also deal with the negative attitudes of nondisabled people towards those who are handicapped. Discriminatory behaviour towards disability does not stop with the individual who is disabled but is extended to the person's family as well. For example, in some Asian cultures the appearance of mental retardation in a family member implies bad blood in the family. Therefore, the stigma of disability is carried by the entire family.

Class is a complicated term. An immigrant woman may belong to one class position prior to immigration but finds that upon entry into

Canada she is placed into another class position simply because she is an immigrant. The majority of women who come from upper class families, especially those who come from Asian and South European countries and who do not speak English or French, find themselves experiencing downward class mobility. On the other hand, those of lower class background may experience upward class mobility because of their improved economic position; whereas in their old country they were living poorly.

Unfortunately, people of the wider Canadian society seem to assume that all visible minority immigrants who entered Canada are generally from the lower socioeconomic class. Yet, the fact that immigrants come from different social backgrounds. The fact that a large number are employed at the lower end of the labour force may give this impression; but those who find themselves doing menial jobs may have had highly respectable positions in their country of origin. This is because the social class relations between the ethnic and racial dominant groups and ethnic and racial minority immigrant (and non-immigrant) groups under advanced capitalism are often ignored (see Li, 1988). Some immigrant mothers of disabled children from middle or upper classes may find it very difficult to transplant their class status from their homeland to the new country.

Social attitudes toward immigrants of colour and the determination of white Canadians to maintain the status quo and privileged position are two factors which play major roles in keeping these immigrants in their assigned low class status. Conversely, class factor is an important shaper of these women's immigrant experience as well as their experience as mothers of children with disabilities. Individuals' expectations of health care and social services may differ because of the mother's class background prior to coming to Canada. These expectations migrate with the women even though their class status does not. An example is the manner in which mothers from different classes are expected to be treated by health care and social services staff. Those from privileged background and who have been highly educated would expect a great deal more respect from staff members according to their status than those from other classes. However, the frustration arises when these women encounter a disjunction between their old country class status and new country status. Immigrant women from lower class backgrounds have no such preconceptions and expectations since their low socioeconomic position remained the same in Canada. Class transition is perhaps less of a problem among this group of immigrant women.

The many diffculties immigrant women face in coming to Canada have been extensively documented in previous research. Broadly speaking, the problems of migration for women are similar; only the special circumstances surrounding the problems may differ vastly or slightly from woman to woman.

2.1 Re-Conceptualizing Visible Minority and Immigrant Women

Many scholars and immigrant women are becoming aware that any inquiry into the lives of immigrant women must proceed from the viewpoints or standpoints of women themselves. The central tenet is that the experiences of immigrant women are shaped by a different set of social, economic, and political conditions than those of men. Therefore, the experiences of women cannot continue to be subsumed under those of men (Anderson, 1987). Nor are they the same as those of non-visible minority women (see Szekely, 1990). The experiences of white middle-class women do not reflect the experiences of visible minority middle-class women (Dua, 1992). Moreover, the experiences of visible minority immigrant women differ within each ethnic group and between ethnic groups (see Szekely, 1990; and also Boyd, 1990; Li, 1988; Hessler et al., 1978 and Pelto and Pelto, 1978 on inter- and intraethnic group differences).

The concept being advanced in modern literature is that of difference or diversity among immigrant women in general. There is growing criticism of works of social science, governments, health system, and Canadian feminist theory which assume that both immigrant women as a whole and the subgroup of racial and ethnic minority immigrant women are uniform, homogeneous, and undifferentiated in their experiences as immigrants and as visible minorities. This remark expresses a similar critique with regard to conventional thinking on immigrant women as well. When ethnic or racial groups were studied they were frequently treated as a whole and seldom as made up of individuals. In highlighting homogeneity, differences between individuals members of the same ethnic group are ignored. This is also true when all visible minorities are treated in a like manner.

Szekely (1990) is a strong proponent of the idea of difference. Her opinion is that immigrant women as a whole share only two common features: being immigrants and women; otherwise, they are very different from one another. Each immigrant woman migrates with a social and personal history that is different from other immigrant and Canadian-born women. Because of their particular individual social, economic, cultural, gender, ethnic, and religious variables, the situations of immigrant women are dissimilar to each other in many respects. Szekely says that to understand the experiences of these women in Canada one must examine the intricate interrelationships of employment, class structure, race and ethnicity, and gender, and other differences among women (p. 125).

The author opposes the theoretical approach which sees class, social, educational, gender, and other differences between immigrants and the Canadian-born women as cultural or ethnic. When differences are construed as culture clashes or value differences, class exploitation and gender oppression of immigrant women are concealed and, the women, in turn, can be blamed for their failure to assimlate into Canadian society (p. 131). Thus, from Szekely's point of view, when cultural or ethnic differences are used by social services, health and other professionals to explain the social and economic differences between women who are immigrants and Canadian women, immigrant women's situations become reduced to culture. They naturally assume that the solutions must also be cultural.

However, it is not so much physical or social characteristics that make a person a visible minority, nor does legality make an individual an immigrant. Rather, the terms are socially defined and constructed in the interaction between women from non-white countries and members of the Canadian culture. As Ralston (1988) states: "[T]he experience of South Asian immigrant women is fundamentally a social matter, not an individual attribute" (p. 64). Being ethnic and being a visible minority in Bannerji's (cited in Mukherjee, 1990) view - she has been living in Canada since 1969 - means that

> [i]t is southern Europeans, sometimes, and Third World people who have to be ethnic . . . It means that we are not considered to be Canadians. We are 'immigrant women'. This is a prominent category. They don't talk about us as Canadians (pp. 147, 146).

It is clear that there is a real need to clarify what is meant by the terms immigrant women and visible minority women. A first step is to recognize that the categories immigrant and visible minority have been created by social practices and policies and are used to describe a person's positions in Canada rather than that person's personal attributes. Secondly,

> [n]ot all people who are technically or legally immigrant are identified or identify themselves as such. Most immigrants from the United States and Great Britain are two obvious examples. Similarly, one may be Canadian-born and -raised and still be treated as an immigrant. Japanese and Chinese Canadians and other visible minorities, for example, are often seen as immigrants. These persons only become immigrant as a result of definite social processes that stamp them with the identification immigrant, which is synonymous with "ethnically and racially inferior" (Szekely, 1990:127).

The dominant ideologies which belie the terms are apparent in the mainstream social organizations. In policies and processes, these social systems often reinforce the myth of immigrant and visible minority as synonymous.

In addition to racial discrimination, visible minority immigrant women must also cope with gender oppression and class discrimination which enlarge the terms immigrant and minority. Yee (1987) may be referring to the situation of Chinese Canadian women but her comments could apply to any ethnic group of visible minority immigrant and non-immigrant women:

> Chinese Canadian women have had to cope with the immutable dilemma of being both non-white and women in a white and male dominated society. This makes us doubly invisible and doubly silenced socially, politically and economically, and through history . . . Sexism and racism are systemic structures of power which define the parameters of our day to day lives and our future opportunities. But our experiences of those sexist and racist structures are very individualized . . . (p. 174).

The position of visible minority immigrant women in the Canadian class system is also determined by the underlying ideology of sexist and racist structures. This is most evident in the labour force. For example, the superior class position enjoyed by middle-class professional South Asian women is difficult to reproduce or maintain in the Toronto job market. As South Asians they are an immigrant of different skin colour and as women they occupy a subordinate gender position determined by western gender ideology (Ralston, 1988:73). Moreover, Szekely (1990) argues that attaching class differences to the individual's cultural or ethnic differences conceals the exploitation of these women in the workplace. It also hides the fact that a greater proportion of immigrant women are employed in the labour market than Canadian-born women.

A case in point is the 'family class,' whereby married women can immigrate to Canada as dependents under the sponsorship of their husbands. Embedded in this class is the western, patriarchical assumption that the man (husband) is the family head and primary wage earner and the woman, in her subordinate position as dependent (not as wage-earner), stays at home to look after the home, children and husband. Women's social isolation and loneliness within their domestic sphere, the demands of family life, the barriers to language training, and the pressure of paid work and unpaid housework are problems produced by the underlying Canadian ideologies behind the 'sponsored dependent class' and other immigration policies and practices.

Visible minority immigrant women in Canada cannot be expected to remain under the financial responsibility of their husbands for a period of up to ten years.

> [E]conomic circumstances in the lives of the majority of immigrant families make it necessary for women to enter the paid labour force, where they find themselves in the lower echelons of the labour market pyramid. Many women, especially those from non-Western nations, usually lack the language and skills necessary to secure well paying prestigious jobs. Furthermore, some highly educated women find that their qualifications from their countries of origin are not recognized in the host community . . . [W]omen's lives are complicated by the demands of family life, and for some, a drastic shift in their lifestyles (Anderson, 1987:411).

One lifestyle change is engaging in paid work outside the home after coming to Canada. However, the women are still expected to do housework. The difference is that the social support networks familiar to them in the home country are seldom available in the host society.

Gender, class and race are an integral part of the experiences of visible minority immigrant women. Like the terms immigrant women and visible minority women, they must also be seen as social attributes, not individual attributes, which are constructed in the historical and ongoing processes of social relationships between people (Ralston, 1988:65). The interrelationships between gender, class and race, and social, economic, and political structures shape the daily experiences of racial minority immigrant women in Canada. Through them one can identify how race and class discrimination and gender oppression in the home, in the labour market, and other social, cultural, political institutions or organizations are created and even maintained.

Szekely (1990) says that many visible minority women are reminded of their ethnic and racially inferior status through society's tendency to perceive and treat them as immigrants. Being seen as an immigrant, in her view, is synonymous with being seen as different: "as foreign intruders, representatives of alien races, strange religions, threatening political views . . . [and] virtually unassimilable" (pp. 127-128). Such racist attitudes are even more obvious if one studies Canada's past and current immigration practices and policies. Most visible minority women who were Canadian-born or raised have found themselves treated as immigrants. They felt that members of the dominant culture society seldom looked beyond highly visible characteristics, such as skin colour, distinct facial features, and, for some, accent, and into the individual and her particular identity and social history. A majority of Canadian-born or raised ethnic minority women, in the eyes of the dominant group, have been unjustly and incorrectly labelled with the racist and homogenic identification immigrant. Szekely (1990), who refers to herself as a white, educated, and privileged immigrant, expresses well the position of immigrant women:

> As individuals we are also very different from one another. What we do have in common is being immigrants and women, but because of our racial or ethnic, political, religous [sic], and other differences our situations differ greatly. We cannot simply say that all immigrant women have a common lot - or a common enemy. In terms of employment, for example, immigrant women constitute two distinct groups in Canada. One group of immigrant women work in well paid professional or managerial jobs, while women in the other much larger group are among the lowest paid and most exploited workers (p. 129).

Immigrant women's actual life experiences are shaped by their particular set of attributes, which play a role in the social and gender relationships between immigrant women and the dominant society. For example, the burden of gender oppression or racism is not the same for all immigrant women. For immigrant women whose physical appearances are similar to the mainstream population, racist discrimination would not be as a significant problem. Neither should we assume that immigrant women possess a somewhat uniform set of attitudes, values, beliefs, and behaviors because they are women and/or immigrant and/or physically visible or non-visible. Hessler et al. say (1978) that this line of thinking in the area of ethnic studies is unwarranted stereotyping which can create the wrong impression of the ethnic group being studied (p. 348). The authors argue that research on ethnicity should start with theoretical paradigms based on the premise of diversity (p. 362); or what Szekely (1990) calls the concept of difference.

Furthermore, it has been argued (see Anderson, 1987; Dua, 1992; Meleis, 1991; Ng and Ramirez, 1981) that visible minority immigrant women perceive their actual life conditions within the households or in the work-place differently from other women. Although racial discrimination by both Canadian men and women against women of colour exists in the workplace, visible minority women may not identify certain behaviour or attitudes as racist (Anderson, 1990). Dua (1992) offers another perspective on gender oppression:

> For South Asian women, the family [which South Asian feminists claim is transformed in the historical context of a racist capitalist society], is not, however, simply a site of gender oppression but, as importantly, a refuge against racism . . . Whatever inequalities exist in such households, they are clearly also sites of support for their members . . . in the context of harassment and attacks from white people (p. 8).

Gender oppression within South Asian families, as perceived by socialist feminists, is based on culture (South Asian) or patriarchy. Women's adherence to traditional culture practices in the home perpetuates patriarchy and women's own oppression. South Asian feminist theory, on the other hand, focuses primarily on the importance of culture in the lives of South Asian women as a form of resistance to racism (Dua, 1992:8). Racism, then, becomes more important than patriarchy. Dua is uncomfortable with the fact that both feminist theories have placed racism and culture above gender oppression. Her point is that they fail to identify realities of South Asian women in the family. These women may use the families and culture as refuge against/resistance to outside racism. But they are also aware that the family is where women's activities are defined and restricted, where paid and unpaid work are appropriated by men, where women are expected to transmit home culture and values to the next generation, where gender inequalities are reproduced and maintained by both men and women.

However, despite the emphasis on diversity or difference in new social science thought on ethnicity and immigrant studies, homogeneity between and within ethnic groups of immigrant women should also be an important consideration. Within each ethnic group, women are often homogeneous in terms of religion, ethnic language, cultural practices, and other aspects but may differ in their educational level and professional training. However, immigration policies and practices and the social construction of gender and race relations determine to a large extent that a large population of immigrant women, whether they are visible or nonvisible, highly skilled or semiskilled, is solely responsible for childcare and other household activities and work in low paid, ghetto jobs. Gender oppression is a serious issue for all women, but for women living in advanced capitalist countries, gender oppression become a double dilemma because of the frequent embedded contradictions. Visible minority women must also struggle with a form of gender relations that is created by the patriarchy of her own ethnic culture.

Scholars who study immigrant and visible minority women have said that the social experiences of all immigrant women must go beyond their everyday life (micro processes) to the larger society (macro structures, such as social, economic, and political ideologies) (Anderson, 1987; see also Ralston 1988). As we see above, gender ideologies of the dominant and home cultures in separate, albeit similar, processes relegate women to a subordinate position in both domestic sphere and in the labour market. Many visible minority immigrant women, such as the South Asians/Indo-Canadian women in Anderson (1987), Dua (1992) and Ralston's (1988) studies, mentioned the contradictions in their domestic life between the ideologies which underlie home culture and the host culture's gender relations. For example, the majority of women found that the host society, like their own home culture and in other cultures around the world, expected women to have the full responsibility of child care and housework in the home (in the domestic/private sphere), whereas the men were to assume the extra-domestic role, as primary wage earner for the family. The asymmetries between the sexes and the opposition between the private and public domains have been the focus of Western feminist work. It has been noted that the subservient position of women and the devaluation of women's activities to those of men appear to be universal (see Ortner, 1974; Rosaldo, 1974).

However, immigrant women in the host country are expected to accomplish child care and housework alone, without any assistance from female relatives, neighbours, and friends. The female informal support network in the home culture is broken for women when their husbands decide to emigrate to Canada. Isolation and loneliness were two common initial reactions to the new culture by many immigrant women. Most immigrant women try to overcome these problems by working outside the home. In this respect, women's participation in the labour market may be less from financial necessity than as a source of social life, even if this means juggling paid work with unpaid work in the home.

Culturally-defined gender relations in both male-dominated home and host countries have determined women's position and role in the domestic sphere. Household activities are the sole responsibility of women, whether she works outside the home or not. Anderson's (1987) opinion is that the lives of the Indo-Canadian and Greek immigrant women in her study are similar to the majority of women in Canada. She cites Burch's survey on family history showing that the double burden of housework and paid work continues to exist for Canadian women. Similarly, many immigrant women take on jobs that are usually low paying and menial, and difficult to move out of, especially for non-English speaking women. Anderson makes the good point that English language skills are important in the development of a wide network of supports; otherwise, women become trapped in a limited social environment of menial jobs and family responsibilities available to the unilingual women (p. 419). For many the idea of leisure is non-existent because of a woman's perception of her responsibilities or duty as a woman. Some of the female participants in Anderson's study complained of tiredness, exhaustion, stress, anxiety, and other health problems. This statement by an Indo-Canadian woman typifies the lives of women:

> It is hard to shoulder the entire responsibility and manage work, family, and other family responsibilities. I cannot think or talk about leisure time. Work is a must. All family responsibilities are a must, and keeping family ties and community links are equally important. There is no choice. None of these things can be deleted (p. 419).

However, this Greek woman's life and the lives of other immigrant and non-English speaking immigrant women differ from those of Candian women:

> First of all, when I first arrived in Canada, I had children, and I couldn't go to school. Later, I had to work, and that short time that I had free, I looked for work, because I had need for money. If I did not have the need for money, the hours I was working I would have gone to school to learn English. But I could not do this, because I had a need for money (p. 421).

Many immigrant women, must earn money to increase family income, albeit doing menial jobs, and this is a higher priority than language learning and marketable skill training. Nyakabawa and Harvey (1990) list several reasons for low-status employment among immigrant women, such as a sex-segregated job market which means bottom rung jobs are more readily available to women; undervaluing of qualifications from the country of origin; different educational and occupational training; and lack of the dominant culture's language skills. On the other hand, immigrant women are also found in the highest echelon of the labour market, but sadly absent in the middle management or white collar positions. Boyd (1990) explains that:

> Language knowledge is a powerful factor in determining labour market location. Women who cannot speak English or French are absent from occupations performed primarily in the host language. In contrast to nearly four-fifths of the Canadian-born women and two thirds of the foreign-born women who know English or French, less than 4 percent of those without such knowledge are in clerical, sales or other white collar

> occupations (including magerial and adminstrative) . . . Immigrant women born in Asia and in Southern Europe are the least likely of the major birthplace regions to know English or French. Approximately nine out of ten immigrants who do not know English or French well enough to carry on a conversation are born in South European or Asian countries (p. 285).

English language skills and marketable skills training are essential for moving out of low-paying jobs (Anderson, 1987). Low status jobs also have very little job security, minimal or no benefits, and few chances of upward mobility (Nyakabawa and Harvey, 1990). Even household chores in Canada require a different kind of knowledge (i.e., learning how to use a vacuum cleaner, to prepare meals on an electric stove and without the usual, familiar ingredients), and are largely performed alone (Ng and Ramirez, 1981). Men and other family members seldom participate in domestic work. In any case, help with housework still does not free women to pursue their own leisure interests or self-improvement. Anderson (1987) explains that it is important to consider how women perceive themselves and how their families perceive them.

However, Ralston (1988) in her study of South Asian women found that our understanding of the experience of these women was coloured with stereotypical myths of domesticity and subservience (p. 70). Most of these women sought paid or unpaid work outside the home or talked on the phone with other South Asian women to combat isolation, loneliness and gender subordination. Working outside the home gives them financial and social benefits, positive self-esteem and self-perception, a certain amount of independence and some control over their own lives.

Through the recent efforts of scholars, various social and cultural factors and ideologies which have worked to keep racial and ethnic minority immigrant women invisible (a contradiction in terms in their actual lived experiences) are being challenged. There is concerted support for an analytical framework which focuses on the dimensions of class, race, and gender and how these variables intersect to shape the lives of women (Anderson, 1987; Dua, 1992; Ralston, 1988; Szekely, 1990). Begum (1992) also sees the value of such an analytical tool applied to the study of women with disabilities:

> I will argue that the experiences of disabled women must be seen as an integral part of the social, economic, and political structures which serve to control our daily lives. I recognize that disabled women cannot be treated as a unitary group: factors such as types of disability, race, sexuality and class will influence our individual experiences and these may differ from the experiences of other disabled women (p. 70).
>
> To avoid the dangers of feeding into cultural misunderstandings and racist stereotypes, we urgently need a thorough investigation of the experiences of black disabled people. We could then develop an analysis of our position as black disabled women and articulate our particular needs . . . However, the way in which we experience and interpret these issues is likely to differ as the dimension of race interacts to shape our lives (p. 71).

The implications of what Begum has written can be extended to visible minority immigrant mothers with disabled children. The experiences and concerns of the mothers in raising a disabled child are likely to differ from other mothers with disabled children as the elements of race, class, ethnicity, disability, and gender interact in diverse ways to shape these mothers' lives.

Visible minorities "is a catch all phrase for people who are identifiably non-white *and/or* non-Caucasian. The term includes not only those who were born abroad [and categorized as immigrants when they entered Canada] but also Canadian-born of Visible Minority parentage" (Samuel, 1988:93). When the term visible minority is used in the present study, it is basically referring to a certain population that is non-white and non-Caucasian, vis-a-vis Asians, Latin Americans, South Asians or Black Asians, Southeast Asians, Blacks, Middle Easterners, West Africans, and Pacific Islanders, and was born abroad.

From the end of World War II to the present, the number of women emigrating to Canada has risen steadily; and in many instances the number of women entering the country exceeds the number of men. Four out of ten permanent residents age 15 and older have been female in this period of time (Boyd, 1990:275). In the past, immigrants coming into Canada from both white and non-white countries were largely males, and it was not till the 1960's that the number of female immigrants surpassed that of males (Herberg, 1989:192).

In addition, prior to the changes in the criteria for admissibility in the1960's and 1970's, most of the immigrants came from traditional sites of immigration like the United States, the United Kingdom and Europe (Boyd, 1990:275). However, the 1970's saw an increasing number of immigrants from other areas, such as Africa, Asia, Central and South America and the Caribbean. By 1987, 70% of immigrants entering Canada were from these countries.

The number of women immigrants has grown in size and significance over the last few decades. The 1981 Census of Canada illustrates the dramatic shifts in male vis-a-vis female and traditional source areas vis-a-vis other areas. For example, only 1.1% of foreign-born Asian women (2.1% of foreign-born Asian men), 0.2% of foreign-born African women (and men), and 0.6% of foreign-born South American and Caribbean women (and men) aged 15 and older were identified as permanent residents of Canada prior to 1946 (Table 2, p. 277). The foreign-born Asian women population rose to 38.9% (41.3% for men), 4.6% for African women (5.7% for men), and 15.0% for South American and Caribbean women (13.2% for men) between 1976 and 1981 (Table 2, p. 277). These percentages exclude Canadian-born and Canadian-raised (under age 15) ethnic minority women and men.

The changing demography of ethnicity in Canadian society reflects the changed criteria for admissibility in the immigration regulations of 1962 and 1967, and in the 1976 Immigration Act. The government eliminated the previous criterion of national origin, which supported the entry of European origin groups and deterred others from non-European countries. Admission into Canada since 1976 was based on labour market skills, family reunification, and more recently, refugee claims than on national origins (p. 275). These changes are having an impact on the ethnic enclaves. Where once they were composed predominantly of married men and single men who had to leave wives, mothers, sisters, girlfriends and children back in their country of origin, now these same communities are inhabited by reunited families and recent arrivals of whole-families. With women joining their male family members, both Canada and the United States are likely to experience an increase in the population of young people. Most of the women who migrated to Canada in the last few years are of childbearing age.[1] Some of their children may have a physical or developmental disability.

According to a Canadian textbook about exceptional children (Winzer, Rogow, and David, 1987), the incidence of disability among cultural minorities is estimated to be as high as that for the general population, if not higher. Eight to twelve percent of school-aged children are considered exceptional in the general population. Culturally different handicapped children are represented in all categories of disability or exceptionality: mental retardation, emotional disturbance, visual impairment, hearing impairment, and speech and language disorders (p. 544). However, the authors failed to indicate what proportion of the eight to twelve percent of the general handicapped children population are culturally different disabled children. The definition of culturally different handicapped children, as intimated by Winzer et al., and as far as I can determine, included Native Canadians, Canadian-born ethnic minority, and foreign-born children who had been medically diagnosed as having a particular developmental and/or physical impairment. However, all these groups were lumped together under one classification.

---

[1] Boyd (1990) notes from the 1981 Census of Canada that the majority of those who were aged 15 and older came from Asia, Central and South America and the Caribbean; whereas prior to the 1970s, immigrants who were aged 15 and older were largely from the United States, Europe, and the United Kingdom (p. 275). Between 1976-1980 a total of 243,489 (52.4%) women over 15 years of age entered Canada as permanent residents (Table 1, p. 276). And according to Boyd's Table 2 59.4% of foreign-born females over the age of 15 came from Asia (39.8%), Africa (4.6%), and South America and the Caribbean (15.0%) between 1976 and 1981 (first five months only) (p. 277).

Based on the age break-down of the 1981 Census of Canada, 91.2% of the total number of female immigrants who entered Canada between 1981-1985 were 15-64 years of age and the remaining 8.8% were 65 and older (Table 1, p. 276). However, in Table 4 (Selected Social, Demographic and Economic Characteristics of Ages 15-64, for Foreign-born by Sex and Knowledge of Official Language and for Native-born by Sex) of Boyd's paper, 48.7% of the total female foreign-born immigrants who came prior to 1946 and and up to 1979 (27,872 out of 56,053 foreign-born immigrants) were between the ages 45-54 followed by those between 35-44 (45.6%), 25-34 (39.5%), 55-64 (48.1%) and 15-24 (18.1%) years of age (p. 282). Women of child-bearing age who may have a physical or developmentally disabled child would most likely be in the age range between 25-34 (39.5%) years of age. And the majority of foreign-born females entered Canada between 1966-1979. An interesting point is that the number of foreign-born who do not know enough English and/or French well enough to carry on a conversation for both male and female immigrants were increasingly higher over the years than those who know one or both of Canada's official languages.

Boyd's (1990) research on the socioeconomic position of foreign-born women, particularly recent arrivals from Asia and South European countries with little or no English or French language skills, compared to Canadian-born women and foreign-born males, revealed clearly the former group's unequal and disadvantaged position. The inequalities of immigrant women, argues Boyd, come from two sources: ethnicity/country of origin and the extensive sexual inequality in Canada (pp. 278-279). Sex segregated occupational and industrial structures mean that foreign-born women, like Canadian-born women, earn less money and fill different types of employment from foreign-born men.

During the time period of the literature surveyed, there was a dramatic rise in published materials on visible minority immigrant women in recent years in Canada, the United States, and Britain. Issues related to migration have been well studied, and there is no shortage of information on this topic; however, it is only in the last few years in Canada that the everyday concerns of immigrant women have been addressed (Anderson, 1987) and in other Western nations as well. Many studies were produced by visible minority immigrant and non-immigrant (Canadian-born) feminists themselves. This was in response to their dissatisfaction with their absence, submersion, inaccurate portrayals or misrepresentations (i.e., racist stereotypying), in the broader feminist movement, multicultural movement, health care system, and at all government levels. Also criticism has been directed towards the use of mainstream social sciences and feminist approaches to analyze their realities and needs (see Shin, 1992). These approaches, critics argue, are based on the experiences of white middle-class members of the dominant culture (see Dua, 1992; Szekely, 1990). More importantly, the everyday experiences of ethnic and racial minority Canadian-born and immigrant women are different from each other, from those of men and women of mainstream Canadian society and from those of men within their own ethnic communities.

Immigrant and visible minority women have become more political and active in academic institutions, government agencies, and grassroot organizations, which challenges and dispels the traditional stereotypes of women from these ethnic communities in Western nations - namely as uneducated, passive, difficult to organize and politicize (Shin, 1992; see also Szekely, 1990). In addition, there is a growing awareness that past studies do not reflect the realities and needs of these women because of the tendency of the mainstream scholars to base the needs and circumstances of the women on their own Western-based perspectives.

CHAPTER III

VISIBILITY AND HEALTH: IMMIGRANT WOMEN AND HEALTH CARE EXPERIENCES

There are few useful studies on visible minority immigrant women caring for their children with disabilities in Canada. There is, however, a substantial body of literature on the health care needs and behaviour of racial and ethnic minority groups in Canada and in the United States.[1] Parents who have children with disabilities are expected to be heavily involved with the health care system to ensure the children will be able to develop to the potential their particular physical and social limitations allow. For chronically or critically ill children, parental involvement is even more crucial; immigrant mothers of disabled children are no exception. As soon as a child had been diagnosed as having some type of disabling condition(s) at birth or as a result of an accident later on in life, the child and his/her family immediately or soon after enter a world filled with clinical assessments and treatments, rehabilitation, physiotherapy, and other special education and intervention programs and services. Although Meleis (1991:370) is referring to immigrant women in general when she states that immigrant women are expected by the host-country health-care system to support its views on preventive health care, the same can be said for immigrant mothers raising children with disabilities.

---

[1] It should be made clear that this chapter's discussion is based on two types of literature from three countries primarily. On the subject of the health care needs and behaviour of immigrant and ethnic minority groups I draw from research evidence of Canadian researchers. One reason is that we do have available information on this topic. A second reason is that since this study concerns Canadian immigrants I have tried to use Canadian sources where they are available. The lack of Canadian literature on visible minority immigrant women caring for children with disabilities in particular and ethnic minority immigrant and non-immigrant parents with disabled children in general necessitated looking at other advanced capitalist countries with large visible minority populations for information. Here, the United States and Britain were found to be most productive in terms of research studies in the area of ethnicity and disability. These studies provide us with some understanding of the life experiences of visible minority immigrant mothers and their handicapped children in Canada. Because of the lack of Canadian research studies on this group of women, the American and British studies, albeit few in number, are highlighted when discussing the experiences and needs of ethnic minority immigrant mothers caring for disabled children at home in Canada.

The concerns being addressed in these works are on the whole concerns of visible minority immigrant mothers and of their disabled children. For example, disabled female children in the future will be experiencing problems similar to those explored in several articles concerning contemporary disabled female adults. This group of visible minority immigrant mothers, on the other hand, will experience common barriers in the existing mainstream health care system as do other visible minority immigrant women, and these difficulties may have a great effect on their response to health and illness situations, such as in the case of chronic health problems (e.g., seizure activities) associated with the child's specific disabling condition (e.g., an insult to the brain). One such barrier relates to the view health-care professionals have of immigrants. This has the tendency to heighten an already stressful situation for immigrant women (Meleis, 1991) and intensifies the women's sense of being misunderstood (Anderson, 1987; Meleis, 1991).

The life situation of visible minority immigrant women is complex and problematic. They face an endless variety of challenges. According to Meleis (1991), the popular trend of identifying with and strengthening one's country-of-origin's culture and language in a rising world of multiethnic community living, has produced a group of women balanced between two cultures [host and country-of-origin] and two sets of values [host values and country-of-origin values] (p. 366). Thus bicultural women are constantly trying to find a comfortable balance between two often opposing sets of expectations and values in their daily lives. It also means having to assume multiple identities and play multiple roles (i.e., as immigrants, as minorities, as women, as mothers, as wives, as transmitters of cultural norms [both host and their own cultures], as ethnic, and so on). Roles and identities which are produced from within the larger social context (the ruling elite) and from the women's own ethnic communities.

The immigrant women's world is a world of dualities: two sets of cultural patterns that are very often opposites, two languages, two different women's roles, and two kinds of health care beliefs and behaviours. Those women who had occupied the upper class strata of their homeland also lived in a world of contradictions between old country and new country status systems. Where once they had power because of their family's class position or personal achievements, immigrant women, especially visible minority women regardless of whether they are fluent in English and/or French and/or highly educated, frequently encounter class demotion because of the power relationship between white dominant and non-white immigrant groups. Also, non-white immigrant women as a whole are subjected to a patriarchy which is different from that of their country-of-origin. This is especially true with those who come from more culturally traditional countries or rural regions rather than urban centres. Their subjective experiences on the whole are shaped by this world of dualities, as is illustrated by the literature on immigrant women.

In addition to the notion of duality, Anderson (1987) also points out that the lives of women in general and immigrant women in particular are defined through the ideology of the woman's role but the experiences of non-white women are further shaped by their status as immigrants and non-white women from a Third World nation.

> One could argue that non-white women's experiences are shaped by the history of imperialism and oppression, and are not only the result of their immigrant status. Instead, these experiences have to be understood in terms of their status as non-white women from a Third World nation. So, not only must non-white immigrant women contend with ideologies about women's role, but must also contend with stereotypes that are entrenched within the mainstream culture, which determine the ways in which they are perceived (p. 433).

To bring Anderson's argument to the ethnic community level, it could also be argued that non-white women's experiences are also formed by their interaction and interrelationship with members of their own ethnic communities. The women are constantly being monitored by members of their country of origin to ensure that they respect and maintain the values and mores of their own culture and perform the woman's role according to their culture (Meleis, 1991). The behaviour of these women, whether within or outside the home, is constantly being judged by two groups of monitors. Because of the unique situation of the immigration process, these women find themselves in tension between the demands of their home-country cultural patterns and those of the new host country (p. 375).

According to Meleis, bicultural immigrant women are an at-risk population for physical and mental distress. The

> delicate interplay between several dynamic properties inherent in being a woman and an immigrant . . . [,] between what the host society at large expects of immigrants and what their country-of-origin communities (local or international) expect from them profoundly influences the identities of immigrant women and the nature of the roles they play . . . [, it] may be problematic and stress producing (pp. 365 (in synopsis), 368).

The dynamic properties considered in the article are: (1) immigrant uniqueness versus dominant culture stereotyping, (2) the immigrant's sense of permanence versus temporariness in the host country, and (3) host-country values versus country-of-origin values.

According to the author, these properties create many identities and demands within each role to be played by women. While many immigrant women may be able to balance all these out, others find themselves at a loss with the conflict and overload of roles, identities, and values from, quite often, two diverse cultures. Immigrant women's health care behaviour and decisions are affected, for instance, by a woman's sense of temporariness or permanency in the host country. As suggested by Meleis, an immigrant woman's sense of temporariness may be a strategy for coping with the stresses of living in a new culture (p. 370). Later she concludes this section of her discussion with a strong and apt statement:

> Understanding health-care behaviors and decisions of immigrant women is related to the immigration status and to the immigrants' immediate and long-term plans in the host country. Although this information is difficult to collect, it is necessary: It is not enough to rely on subjective data such as language, furnishings, and clothes . . . to come to grips with the situation of immigrants (p. 370).

Furthermore, immigrant mothers' health care actions and decisions also influenced their particular class status. Middle- or upper-class immigrant women have more resources or access to resources than immigrant women less well off to help ease some of the the problems faced by all immigrants living in a new culture. For instance, there is less pressure for middle- or upper-class immigrant women to join the labour force as soon as possible. However, financial security cannot eliminate all the problems experienced by visible minority immigrant women from various economic class levels when factors such as racism and sexism still exist in our society.

For immigrant women raising children with disabilities, these aspects comprise only a part of their actual living situation. Unlike their immigrant sisters, these women face other problems which set them apart: having to care for a child with disabilities; close involvement with the health care systems and special school systems; and battling with the host-culture and country-of-origin community's attitudes toward individuals with disabilities and their families for bringing shame to the community (e.g., Chan, 1979). Because of these additional factors, the mothers occupy a position below that of other immigrant women with non-disabled children. If they are physically visible also, then their place is even lower than other visible minority immigrant mothers of normal children. As Meleis (1991) points out:

> Even for those who have managed to maintain that delicate balance [of the properties identified], certain life events or milestones that increase the demands or raise more identity issues may increase their health risks. Such events and milestones may be an illness in the family of origin, locally or

> internationally, a birthing experience, becoming an elderly person, having a teenager, or experiencing a loss (p. 371).

One could add to this list of life events - having a handicapped child.

Although many immigrant women may be comforted by the fact that they have the option to return to the homeland, especially for elderly women, such a pressure-release valve is not realistic for those who have migrated as political refugees. For immigrants whose children need the best and most advanced special health care and educational services the alternative of return does not exist. In many Third World nations there are no specialized services and programs, or else they are too expensive for the immigrants who are often from the lower income class. Attitudes towards people with disabilities are generally very negative and discriminatory. Immigrant visible minority parents of children with disabilities are well aware of the advantages for their children with disabilities and for themselves in the host culture. This is what Mexican American parents said to Mardiros (1989) during the interviews :

> Services for the disabled have not been readily available in Mexico. Most parents acknowledged how fortunate they were to live in the United States, that services were available for the child and that the attitude toward the disabled was positive and accepting, assuring the child a place in society. The following comment represents the view of a number of parents. "In Mexico they don't care that much about retarded and handicapped people. It's a luxury. The low income people don't have doctors because no money. The rich people put them away. Like on ranches. You don't see the disabled that much, you hide your child, not to church, or mercado (market) . . . " (p. 65).

In the Third World where the majority of the people live in extreme poverty, everyone in a family is expected to contribute financially to the family's survival. Having a child who needs to be supported for life rather than lending support is considered a misfortune not a blessing (Moyes, 1981; Shirley, 1983). Severely disabled children have been known to be abandoned, rejected, ignored, or neglected by their poverty stricken families.

A positive social attitude makes it easier for visible minority immigrant mothers to accept the child's disability. However, the lives of these women as visible minority immigrants and as mothers to disabled children are still subject to discrimination, stressful, conflictural, lonely, and oppressive. The attitude of the husbands, other members of the family, and/or members of their ethnic group toward the mothers and their disabled children has an impact on the well-being of these mothers and their children. In most Asian cultures, the general attitude toward disability are negative and discriminatory. Asian families suffered from these reactions as well as the shame attached to the disability. In turn, the husbands and/or in-laws may blame the mothers for bringing shame to the family by producing a disabled child. This guilt is placed on the shoulders of the women as well as the burden of caring for the disabled child. The women's lives are made easier if the husbands accept the children and participate in building their well-being. Further discussion on the attitudes of fathers and husbands can be found in Chapter IV.

With the health care system's greater emphasis on home care, the immigrant mothers need to consider their own health and well-being because this will have an impact on that of the children, who are often under their sole care. If immigrant women are at high risk for health problems then we can expect these mothers are too, if not more so.

Immigrants are generally perceived by health care providers to either underuse or overuse health services. In particular, the underutilization of mental health centres among Asian American populations has been well studied (Chan, 1979). This applies particularly to ethnic populations which can use their home culture's traditional health care system within the ethnic communities (e.g., the Chinese). The rate of use and the quality of health care delivery to immigrants in ethnic minority groups have been an issue for more than twenty years, and next we will discuss the findings from various studies on this topic.

It is important to discover if the existing health system is serving the needs of the ethnic minority populations of today, especially for visible minority handicapped individuals who may have a life long relationship with the mainstream health care system and professionals because of the severity of their disabilities and the chronic health problems which often accompany them.[2] Also, as Meleis (1992) and Samuel (1988) have pointed out, advanced western capitalist societies need to pay more attention to the changing characteristics of the populations within their own nation. Because of the increasing number of immigrants and refugees these countries are becoming more multicultural. It is suggested here that developers of health care policy and professionals and social scientists pay more attention to the currents of change within the communities and try to establish research strategies, policies, and health care delivery approaches that are attuned to the different ethnic worldviews and different immigrant experiences as health care consumers.

3.1 Immigrants and Health Services: An Overview of User Status

The subject of immigrant health is becoming recognized as an issue because the number of immigrants and refugees in North America is increasing (see Anderson, 1987; Christensen, 1987; Lipson and Meleis 1989; Meleis, 1991; O'Sullivan, Petersen, Cox, and Kirkeby, 1989). Almost 50% of those immigrants and refugees are women (Anderson, 1987). Communities throughout North America, especially in the urban centres, are becoming increasingly multicultural and multiracial. More newcomers are maintaining their own languages, cultural heritages and ethnic identities than in the past (Lipson and Meleis, 1989). Immigrants and refugees are considered potential health care clients because of the endless variety of stressers associated with the immigration process and adoption of a new society. Some disciplines have come to recognize the high risk of recent immigrants and refugees for mental and physical problems, consequently these fields have stepped up their research efforts on the health status and health care needs of these groups (p. 103).

---

[2] Chronic health problems are defined as "permanent, or frequently recurring diseases or medical conditions that interfere with an individual's ability to lead a normal life" (Winzer, Rogow, and David, 1987:561). Each disability ranges from mild to severe or profound. *Exceptional Children in Canada* (1987) by Winzer et al. is an excellent resource book recommended for anyone wishing to know more about exceptionality and where Canada stands in this.

There was growing concern in the 1970's about the wide discrepancy between the utilization of health care and social programs and services between racial and ethnic minority populations and the general Caucasian population. Research findings demonstrate a pattern of limited use and premature termination of community mental health services by ethnic minority clients. However, as Meleis (1991) points out, underutilization is not the only problem perceived by health-care providers. They also complain of its overuse by immigrants. How this is so, the author does not say. Sue and his colleagues (cited in O'Sullivan et al., 1989) conducted several studies of community mental health care (CMHC) services in Seattle-King County, Washington between 1971-1973, and found that existing services were inappropriate and unresponsive to the needs of various ethnic minority and immigrant populations (e.g., Asian, Black, Hispanic, and Native American client groups). The findings showed gross inadequacy of service delivery which resulted in the persistent underuse of the centers by ethnic minority clients and overuse of the same services by Caucasian clients. Sue proposes several ways to enhance service delivery to minority groups. One is the integration of mainstream mental health services with ethnic communities' traditional healing practices (p. 18).

Other recommendations by Sue are: (1) development of ethnic-specific mental health centers with minority communities to parallel mainstream ones, (2) their staffing with ethnic-specific professional and paraprofessional service providers, and (3) the encouragement and funding of culturally unique and relevant treatment and program alongside traditional mainstream modalities. Ten years after Sue's seminal work some of the recommendations had been adopted in the Seattle-King County area. Mental health centers for ethnic clients have been established in the aforementioned ethnic communities; the number of ethnic-specific professionals and paraprofessionals staffing the centers and mainstream centers has been increased; and a state-wide support of culturally sensitive treatments and programs has been procured.

A decade later, O'Sullivan et al. assessed the effect of the changes in the county's community mental health service delivery system on the utilization patterns among the same ethnic minority groups. They found that the rates of utilization had dramatically increased among ethnic minority groups; with Asian Americans having the biggest representation in the county's client population compared to a decade ago (from 2.4% to 4.6%). The CMHC system also manages to retain its ethnic minority clients. However, the authors felt that the influx of Asians and Hispanics around the time of the study may have contributed to the significant rise in the number of clients using mental health centers, and was not indicative of increasing mental disorder problems within the same ethnic populations studied earlier by Sue. Meleis (1991) found in her review of literature that when health clinics are appropriately staffed with bicultural and bilingual persons, immigrants tend to appropriately use even mental health services, which normally are least used by them (p. 371). It seems a language and ethnicity match between clients and service providers improves use of health care services among ethnic minority groups, as predicted by Sue. An interesting observation in O'Sullivan et al.s' study is that the proportion of Hispanic male and female clients was evening out. Sue's study had, in contrast, reported that considerably more Hispanic men than women were clients of the centers. Again, the different rates between the sexes may be due to the large number of Hispanic women migrating to the United States in the early 1980s.

Since then, other scholars have used Sue's work as a baseline for investigative studies of different patterns of help seeking behaviours of underserved populations such as ethnic minorities, children, the elderly, and other subpopulations. In the 1980s, several writers offered a series of hypotheses to explain the differences in health seeking behaviours between ethnic minority and mainstream populations: cultural perceptions of pyschiatric disturbance, cultural styles of help-seeking behavior, cultural appropriateness of the service delivered, ethnicity of the mental health provider, the mental health specialty of the provider (O'Sullivan et al., 1989:18) and cultural values and attitudes (e.g., feelings of shame and guilt, and fear of ridicule or rejection) (Christensen, 1987:196).

North American Asians and other visible minority writers have been trying to dispute the explanations of mainstream health care and social workers and social scientists as to why visible minority and immigrants underuse existing health and social agencies. The general belief that the problems of the Chinese can be taken care of by the family (Christensen, 1987) has much to do with the notion of underuse held by practitioners and researchers. Some Asian writers argue that such a misconception is based on the model minority concept, which is commonly a sociological stereotype applied to Asian groups such as those of Chinese, Japanese, and Korean ancestry (see Chan, 1979). Members of the dominant culture would point to the economic and academic successes of these groups in North America, while claiming that despite many barriers, discrimination, and harsh immigration policies, they have overcome adversity without many emotional or psychological problems. In addition, the strong self-sufficiency and self-reliance so often seen among Asian families and communities, whereby all kinds of problems would be taken care of within the family or ethnic community, have been attributed to perceived strong family ties and a strong sense of ethnic community (Christensen, 1987) or collective responsibility (Chan, 1979).

Historically, visible minority groups dealt with rampant racial prejudice by retreating or turning inward and subsequently erecting invisible or physical barriers between themselves and the dominant society. Major or minor difficulties were mainly resolved within ethnic enclaves. This had been the practice for minority groups residing in the urban centres of North America and other advanced capitalist western nations (Chan, 1979). Another survival strategy among Asian populations is to be inconspicuous or to maintain a low profile. According to Chan, this has caused a dislike of government organizations, and as a result, underuse of them and public health and social services. Moreover, Chan suggests that

> the underutilization of mental health agencies has also been attributed to a common disposition characterized by fatalism - that is, a philosophical detachment and resignation to external conditions and events over which one has no control. This orientation .is often interpreted as "passivity' and falsely designated as a cultural "trait". Asians have thus been stereotyped as "silent, suffering, non-assertive" peoples. This style or orientation more accurately reflects a pragmatic coping strategy which has evolved out of the Asian experience in an alien American culture (pp. 13-14).

This fatalism disposition is also noted with Mexican American (Mardiros, 1989) and Middle Eastern parents in regard to a child who is disabled, which they have explained from within their own cultural belief system as divine intervention. This will be described in more detail in Chapter IV. Suffice it to say at this point that this orientation has led home intervention educators to complain about the parents' passive resignation or hostility towards any treatment or intervention activities for the child (p. 66).

Lack of information or misinformation about health care services and programs have been found to be major barriers to their use among various ethnic minority populations. Often people have misconceptions of mainstream health care services because of their unfamiliarity with western medical practices and lack of knowledge of their effectiveness, cost, and assorted treatment procedures. Chan (1979) describes a number of institutional barriers to the use of mental health services by Asians (p. 15).

A major problem is inacessibility to these services. Centralized urban mental health agencies are effective at serving the general population but are often far from many Asian communities. Many Asians have to rely on public transport to take them there, which often entails a lengthy bus ride. In addition, working parents frequently have problems with health agencies because of insufficient child care resources and limited hours of service of these facilities. Few centres have bilingual staff members or efficient interpreter services. This deters those who lack English language skills. Financial limitations also limit access to alternative resources, such as private services.

Chan describes the fragmentation and discontinuity in mental health practices. He points out the failure of agency staff to personalize their relationship with their clients during intake, screening, and assessment. This, he claims, is due to the fact that these agencies were shaped by the medical model. As a consequence, there is a lack of continuous interaction with the clients, which is alien to Asian clients more familiar with the personalism, sensitivity, and proper attention to those in need of assistance of their home culture's health systems (p. 16). Another major problem with mental health services noted is the frequent failure by policy makers and administrators to include both frontline personnel and the clients in the process of developing programs. They also have been remiss in collecting accurate data on the needs of specific communities, such as the Asian communities. The author saw the omission of the actual needs of Asians in the policies as a form of discrimination because "such policies are manifested in underenumeration of the general Asian population, inconsistencies among institutions in the identification of Asian staff and clients, and persistent failure to recognize Asians as a distinct 'minority' group with significant needs"(p. 17). Besides criticizing problems of accountability with institutions, Chan also argues that cultural insensivity on the part of mental health agencies contributes to the underutilization of existing mental health facilities. This cultural schism is seen in the high drop-out rates among Asian clients (usually after one session) when compared to white clients.

The rapid growth of certain ethnic populations through immigration to Canada and the United States has overtaxed the existing resources within ethnic communities. It has become progressively more difficult to maintain collective responsibility for employment, health, social and other needs within these ethnic communities. As Chan has discovered within the literature on Asian communities:

> There has been a marked reduction in the cohesion of older Asian communities and a corresponding deterioration in

> traditional community institutions which earlier served a preventive or coping function . . . Furthermore, existing indigenous resources have been overtaxed and unable to meet the unique needs of rapidly increasing Chinese, Korean, Pilipino [sic?], and Samoan immigrant populations . . . Other recent immigrants such as the estimated 150,000 Indochinese peoples are faced with the absence of existing community support systems (p. 13).

These circumstances surrounding Asian populations are likely to be experienced by other ethnic and racial communities, especially with newer groups that do not have the long history of migration of other minority groups. New racial minority groups have much need for mainstream medical services and social agencies. However, their needs may be ignored if researchers and persons who deliver professional service continue to use the image of the model minority.

Concomitantly, ethnic and racial minorities should also refuse to conform to this conception of themselves and begin to highlight old and current problem areas which are serious and bring them to the attention of the larger public service delivery systems. In this time of rapid technological and social changes, ethnic and racial minority groups find that cloistering their social, economic, and health problems harms those in dire need of advanced modern health care practices and services that their own communities cannot offer. Yet, Asian groups in North America cannot deny that the myth of model minority had vastly changed their lives for the better within the dominant society. Asians have become respected contributors to mainstream society.

3.2 Diversity/Difference Among Ethnic Minorities: A New View of Health Care Behaviour

An important trend which developed in many of the post-1960s' studies was greater recognition of cultural diversity in health seeking behaviours among ethnic minority groups and intraethnic variations in behavioral patterns within a specific ethnic minority group (see Hessler et al., 1978). This trend is a critique of previous work on ethnicity and health care consumership. As Hessler et al. point out:

> While this research has had impact on the development of middle-range theories concerning the relationships between ethnicity and behavioral patterns, especially illness behavior. . . the studies assume a degree of cultural homogeneity. For the most part, members of the ethnic or racial group studied are treated, theoretically, as if they possess a relatively uniform set of attitudes, values, beliefs, and behaviors. This is particularly true for studies of ethnic groups which are highly visible due to their distinct racial characterisitcs and tenacious pursuit of separateness (p. 348).

The authors conducted a study in Boston's Chinatown to show that there is a great deal of diversity within ethnic communities and variation in health care service utilization behaviours within ethnic minority groups. This is especially true within ethnic communities which have access to more than one health care system, both a Western medical system and an traditional ethnic system. The authors found differences among the Chinese Americans in their management of the two medical systems. Some used the Chinese system exclusively, others would use Western medicine more than Chinese medicine and vice-versa. An important factor was that no one interviewed used Western medicine exclusively.

Secondly, the authors also found that, sociologically speaking, gender has a greater effect than ethnicity on the illness behaviour and attitudes of the men and women in the sample. For example, the number of children in a family was an important factor for predicting the behavior of women faced with family illness, but not for men. In illustration of this point, women with few children, who used the Western medical system more than the Chinese, and women with a large number of children who used only the Chinese medical system, did not favour flu shots. Conversely, women who used the Chinese medical system more than the Western one and had few children, and women who used both systems to relatively the same extent, were in favour of flu shots.

The most important factors in men's patterns of health care use were ethnic solidarity, age, and marital status. Hessler et al.

hypothesize that the traditional sexual division of labour in Chinese culture, where female roles include the larger share of childrearing and males assume the dominant leadership role in the Chinese community, may explain the difference between men and women in Chinatown. However, the authors could not explain why age and marital status were such important factors for males. The study shows that health seeking behaviours within ethnic communities and between men and women in these same ethnic communities are too diverse for social scientists and medicine to assume cultural homogeneity in health care preferences. Another criticism in the article is:

> Rather than designing innovative organizational forms which assume cultural uniformity and reflect, accordingly, modes of operation relevant to a minority of the ethnic group members, health care organizations could be based on research which takes into account the multiple and diverse networks of factors associated with types of medical care received (p. 363).

Christensen (1987), who appears to hold the belief of differences similar to that of Boyd (1990), Li (1988), Ng and Ramirez, (1981), Szekely (1990), and other Canadian scholars, said:

> It must be recognized that the Chinese community is *not monolithic but represents a number of culturally distinct sub-groups*, including, for example, "old stock" Chinese Canadian families, more recent immigrants from Hong Kong and Taiwan, and refugees from countries such as Vietnam. Moreover, like all immigrants, Chinese individuals become bicultural to varying degrees, once in Canada. Most maintain aspects of their Chinese cultural backgrounds while incorporating aspects of the Canadian value system and life-style. Helpers in mainstream agencies must, therefore, guard against expecting all Chinese people to be recent immigrants unfamiliar with the Canadian way of life. *Knowledge of, and respect for, differences* among the Chinese populations *is a prerequisite for a helper to be effective* [my emphasis] (p. 197).
>
> Within any cultural group, a range in definitions of apparently similar situations may be found, and responses to problems

> vary, according to the individual's personal range of acceptable behaviours . . . Furthermore, once those in the individual's immediate environment define his or her behaviour as deviating from the culturally acceptable norm, their responses and efforts to deal with the situation will affect the individual's self-perception . . . (p. 191).

Christensen added that problems and solutions are also determined by factors such as whether one is Canadian-born or foreign-born because, then, there is the question of degree of integration and assimilation. Intergenerational differences in problem perception and preferred solutions are themselves problems within families composed of immigrant parents and Canadian-born children.

The results from Christensen's study of 60 immigrant men and women of Chinese origin in Montreal indicated gender differences (though not of statistical significance) in the kind of support networks used outside the family. For instance, although family was the number one preferred support network for everyone in the sample population, Chinese women indicated less reluctance to seek help outside the family than their male counterparts (p. 194). As a second choice, immigrant women preferred to go to their same-ethnic "friends" with personal or interpersonal problems, while immigrant men chose "other family" members response on the Support Network Questionnaire used in the study. The author did not offer an explanation why the choice differed between Chinese Canadian immigrant men and women. However, Christensen did suggest further investigation into the question of whether traditional Chinese gender division of labour in the domestic sphere affects male-female help-seeking patterns.

In terms of other support networks, only 48% of her respondents claimed they use the Chinese community services, although 87% were aware of their existence (p. 193). However, the people tended to use these services for practical purposes, such as housing and problems with the English/French language. The least preferred source of help was mainstream social services (3%) even though 27% knew of their existence. Non-Chinese aid from a mainstream agency was not considered as a possible source of help by the Chinese studied. In addition, very few Chinese respondents went to a Chinese helper in an ethnic agency or a non-Chinese helper in a mainstream agency with their marital, family, or sexual problems.

The majority of the Chinese sampled claimed to be in control of their feelings and had no serious personal problems. Others preferred to keep their problems to themselves. Christensen admits her study is too limited to allow further investigation into some of these findings. However, she posits that the Chinese cultural value of shame and guilt may explain such a low rate of mainstream or ethnic community resources utilization and high report of no serious personal problems. Among some ethnic and immigrant groups, such as Asian and Middle Eastern cultures (see also Chan, 1979; Lipson and Meleis, 1989), people are honour-bound not to disclose information that may put the family in a negative light to outsiders because of the damages (loss of face) to the family name and honour. For example, if a family member is suspected of or has mental illness it is not revealed to the public for fear of social stigma (Chan, 1979) or harming potential good marriage alliances for other members of the family (Lipson and Meleis, 1989). Such cultures are not likely to disclose serious personal or family problems (e.g., marital or psychological problems).

In addition, Chinese and Korean people seldom complain of psychological problems such as anxiety or depression. These Asians are more likely to present their emotional distress or social problems as bodily rather than psychological or mental complaints (Pang, 1990). For instance, emotion may be expressed in physical symptoms such as discomfort in the chest or abdomen. According to traditional Chinese medicine, which has greatly influenced traditional Korean medicine, the

> internal organs combine physiological and psychological functions. The heart is viewed as the center of emotions and as governing all physiological function . . . The stomach and lungs are considered to be particularly susceptible to ill effects as a result of anxiety, worries, and sadness. The spleen can also be put out of balance by anxiety (p. 496).

Further support for the consideration of diversity or difference in the study of health and illness issues among ethnic groups comes from Pelto and Pelto (1978). They argue that medical anthropologists need to realize that members of a particular ethnic group do not hold the same beliefs, attitudes, and behaviours toward health and illness among themselves, or with other ethnic groups. Nor are views on health and illness homogeneous among professionals in the medical establishment. Pelto and Pelto argue that in treating the beliefs, attitudes, and behaviors of both medical and community people regarding health and disease and health-seeking practices as the same or homogeneous intraethnically, interethnically, or intraprofessionally, anthropologists have neglected the tremendous variability and complexity of medical personnel's and health care users' health beliefs and behaviors. Likewise, Schensul (cited in Pelto and Pelto) has also found intraethnic diversity in health-seeking behaviors in a Chicano group in Chicago. Woods and Graves (cited in Pelto and Pelto) on the other hand, wrote on the intracommunity differences in health-care attitudes and health-seeking behaviors in a Mayan group in Guatemala (the latter two studies are included in a book by Pelto and Pelto, see p. 404). In addition, Woods and Graves provided statistical data showing that economic factors have a greater influence on the health behaviors of the Chicanos than cultural beliefs. This last point also helps to explain why ethnic minorities seldom use mainstream services and agencies.

Historically, medical officials have sought out anthropologists to examine the social and cultural factors which might identify the attitudes by consumers toward the medical establishment. These discussions have been valuable in developing sensitivity and understanding between the doctors and their patients. Anthropologists, Pelto and Pelto notice,

> have been rather closely attuned to the health needs and aspirations of the people they study and have come to identify with them and to accept indigenous health beliefs and practices as efficacious and commendable. This favorable attitude toward indigenous health and curing practices has . . . made a significant contribution to the efforts of anthropologists in

> coordinating traditional and modern health systems (p. 403).

However, warned the scholars, anthropologists need to highlight the diverse attitudes, beliefs, and behaviour of health care professionals and ethnic clients. Moreover, anthropologists should pay more attention to the current changes within the medical system and within the much newer medical establishment, the community health-care system, in their role as cultural broker[3] in the medical field.

> Rather significant changes are taking place in the medical system, especially within the United States. New medical schools have been established which have proposed new definitions of the relationship between medical people and social and/or behavioral scientists. Hospitals are still the central bastions of health care and medical training, but current trends in health care place greater emphasis on ambulatory care, home care, and facilities and services outside the hospital . . . (p. 402).
>
> As people in communities and medical systems go through the process of redefining their relationships to each other, anthropologists must also develop new models for their relationships to both groups . . . An approach to health-care issues focused on uniformist, cultural beliefs and an anecdotal, nonquantified style of research is inadequate for the complexities of all contemproary situations, either within the United States or in other parts of the world (p. 405).

The authors criticized anthropologists for frequently referring to physicians or medical personnel as if they were a monolithic bloc of power and privilege and with the same views and assumptions about health care. One may infer from this an unquestioned acceptance by anthropologists of the high respect and power status society has accorded those who are holders of western medical scientific knowledge. On the other hand, this image of medical personnel by anthropologists may have been an unconscious reflection of a common colonial relationship (a them and us dichotomy) which exists among medical personnel. However, within the medical system, power is not evenly distributed to health care personnel; rather there is an established power hierarchy between staff members. Also, every medical practitioner has her own personal and professional history, and her attitudes and behaviour toward other medical staff and clients are influenced by these factors. Pelto and Pelto argue that a model which stresses uniformity rather than uniqueness of cultural norms and beliefs related to health care within each ethnic minority groups and within the medical system and its personnel is too simplistic: People in communities are as complex in their health beliefs and behaviors as those working in the medical establishment (p. 404). The result is ineffective health care for members of ethnic communities.

---

[3] A culture broker is "a collaborating professional member of the health-care delivery team who serves as a link and mediator between a cultural group and the health care providers" (Willigen, 1991:141).

Even feminist interpretation of informal care in the home as the exploitation of family obligation by the health system is under scrutiny by contemporary scholars. Opie (1992) has found that the caring body (the term used by the author to refer to a family member who takes on the primary responsibility of caring for an ill member of the family) has been generally perceived as uniformly (monolithically) exploited or alternatively uniformly (monolithically) willing in her qualitative research of the everyday experiences of family caregivers looking after elderly members at home (p. 55). Opie's own data contradict this conventional view of the caring body or caregiver. The stress and monotony under which many caregivers labour every day is undeniable, which is why researchers have emphasized the exploitativeness of the role. However, Opie argues that there have been moments of intimacy and tenderness shared between caregivers and care recipients which reduce the tensions of the caregiver and reaffirm the value of the role. It is during these moments that the perception of an uniformly exploited caring body needs rethinking. Secondly, there are other dimensions which have an impact on how the caring body constitutes the caregiver role and the degree of exploitation. The fissure between the experiential (where the caring is not always construed as exploitative) and ideology (where it is) should be included in the analysis (Opie, 1992:55). Furthermore, age, gender, ideology, generational positioning, prior experience of acting as a caregiver, the past and current relationship with the elderly person, and ability to command resources are personal dimensions which must be incorporated into the analysis of the caring body and its subjective experience of exploitation or willingness.

From the various perspectives presented above, ethnic minority immigrants will most likely encounter some serious problems with the mainstream health care system, and even social agencies. Explanations offered in the existing literature regarding the under use of services can be classified under six broad headings: (1) language issues, i.e., communication problems with mainstream health and social workers because of inadequate English language skills; (2) cultural differences, i.e., culturally determined definition of and attitudes toward health and illness of mainstream health care staff versus ethnic minority clients; or the traditional healing system versus the western healing system; (3) a lack of information about existing health care agencies; and (4) strong family support network; (5) traditional cultural values, i.e., in many Asian cultures in North America, such values as self-control and inhibition of strong emotions and strict accountability and obligation to the family have been maintained to a degree. For example, when a member of a family exhibits inappropriate behaviour in public, the entire family is stigmatized and considered to have brought shame to the family name and their community.

Help-seeking behaviours are then influenced by how willing a family is to expose their shame to a member of the host society which already exhibits a negative attitude toward visible minority immigrants. The immigrant family and extended family try themselves to assume the primary responsibility for dealing with any dysfunctional behaviours and/or health problems exhibited by a family member rather than seeking public or mainstream resources. The problem with families taking it upon themselves to deal with a family member with behavior and/health problems is that it produces a high tolerance for that family member's deviant and/illness behaviours. Only when the behaviour creates a major disruption in the the family would external resources be considered (Chan, 1979:12). However, when the family belatedly decides to solicit outside help, the conditions of the ill or impaired person may have worsened and health care providers may get an inaccurate impression of the prevalence of mental illness among ethnic minorities.

The sixth (6) explanation offered by scholars regarding the under use of service agencies by ethnic minorities points to the insensitive and impractical medical treatment process and administrative procedures within them. They are frequently insensitive to the special circumstances surrounding immigrants. The hours of operation reflect mainstream middle-class work habits: nine to five, five days a week. Many non-English speaking and low income immigrants have jobs which do not provide time off during regular working hours for them to seek medical or social help. However, medical services could be obtained from the growing number of walk-in-clinics which are open late in the evenings and on weekends to accommodate the diverse work or family schedules. To use Chinese North Americans as an example, it is understandable that, since Chinese practitioners such as herbalists (healing through herbal medicine is a very ancient popular medical system in China) have the same hours as other Chinese retail businesses (seven days a week and late at night) and are conveniently located in Chinatowns, Chinese immigrants use them more often than mainstream services. The majority of Chinese trust the traditional Chinese medical system, but others try to balance this practice with the use of western medicine (see Hessler et al., 1979), though none of the Chinese Bostonians living in Chinatown reported using only the western medical system.

The impractical and culturally insensitive Western healing practice, reflects the Western capitalist ideology of individualism (Anderson, 1987). As Dossa (1990) describes it:

> The notion of the individual as an autonomous and distinct entity is peculiar to western society and is understood in terms

> of a self-determined as opposed to a socially-determined being (p. 37).

Anderson (1987) describes this notion within Western medicine as follows:

> The perspective prevails that the individual stripped of social context, is able to work out solutions to problems, even when these problems are embedded in the social setting. Difficulties that arise from within the family, that may not just be a consequence of everyday bickerings, but which have to be understood within the total context of the migration experience, become redefined by health practitioners as individual problems, or at best 'family problems' in the sense that the family is a self contained unit, and family members should be able to 'work things out among themselves' (p. 431).

In other words, health problems become constructed as problems within a person. The implication is that there is something wrong with the individual. Western practitioners who are grounded in this notion would try to help the individual person to resolve the problem. Both Anderson (1987) and Szekely (1990) point out that the Western medical model of individualism ignores the fact that the immigrants' health problems are often a result of their life situations, migration experience, minority and class status, and gender roles. The examples given by Anderson and Szekely to illustrate their point will be presented in the next section of this chapter which will focus on immigrant women's perceptions of their health problems and their care-seeking patterns.

There are certain broad health care issues which immigrant members of all ethnic groups share because of their immigrant experience and/or minority status. Family roles, cultural values, economic status, and social position are some of the common issues. However, there are differences in women and men's perception of various stressors and their possible resolutions. Beneath the common health issues are other issues specific to women which come from host country and country-of-origin ideology about women's role and identity. Immigrant men have health problems related to their male roles as the primary family income earner and patriarch in both the family and in their own ethnic community, whereas women experience stresses associated with their responsibilities of child care and household activities and high-pressure, low paying jobs outside the home.

Recent studies of the social context of the individual immigrant family, or a group's migration experience and/or minority status experience have found that underuse of mainstream health systems may have some advantages. The traditionally close family is brought even closer together and can be a positive source of support and a haven against the negativities of the outside world (see Anderson, 1987; Chan, 1979; Dua, 1992). Similarly ethnic communities have the same function as a family but on a larger scale. A negative aspect is that when the family or community becomes the only resource, family members do not seek alternative forms of help; even when the family or community does not have adequate resources to meet their needs.

Moreover, the question arises as to why immigrants are reticent about using the services. Policy makers and health care practitioners would benefit from a better understanding of these two areas; then perhaps immigrants will be more positive about using the services or continue to use them.

3.3 Immigrant Women and Mainstream Health Care: A Visible Dilemma?

In this section I will discuss the health seeking responses, the health care perception of visible minority immigrant women, and their experiences with health care professionals and the mainstream health care system. I will focus on issues and concerns specific to women. It has been argued that immigrant women's experiences cannot be subsumed under those of immigrant men because their experiences are shaped differently. Many feminist writers and researchers have discussed extensively the social and cultural construction of male-female roles to provide insights into the situation and experiences of women (e.g., the pioneer works of

Ortner, 1974; Rosaldo, 1974). Feminist literature argues that women's subordinate position can be explained only in terms of the social relations between gender. Therefore, women are devalued because of their symbolic association with nature which provides them with particular sanctioned roles (reproduction and nurturing) (Dossa, 1990:39). Men, on the other hand, are considered to have the culturally sanctioned valued roles as family providers; in opposition to nature, which gives men their legitimate authority over women (see Ortner, 1974).

The role nurturer places women in one part of another dichotomous category: in the private rather than the public sphere. In the former we often find women performing their 'natural' functions in their culturally prescribed female roles. The circumscribed domestic activities are also devalued because of their association with women's nature. North American societies, according to Rosaldo, emphasize the opposition of male and female, and the distinct spheres for men (public) and women (private/domestic); but these societies are not exceptional. As Rosaldo (1974) observed,

> it is everywhere the case that there are characteristic tasks, manners, and responsibilities primarily associated with women or with men. Cross-cultural studies of child rearing . . . reveal certain temperamental differences between the sexes, and studies of adults indicate that it is women, and not men, who have the primary responsibility for raising children; this fact seems to make it unlikely that women will be society's hunters, warriors, or the like . . . (pp. 18-19).

Immigrant women in Canada and the United States are likely to continue their reproductive and nurturer roles and activities as in their own country-of-origin. Rosaldo (1974) argues that society attaches importance and value to men's roles and activities. Having perused the work of Mead and others on sex roles in various cultures around the world, she (1974) notes an asymmetry in the cultural evaluations of male and female, one which seems to be universal (p. 19).

Rosaldo (1974), then, contends that an analysis of human social and cultural organization, rather than biological considerations, can explain this asymmetry of sex roles and position.

> [M]y point is that what universals can be found in the social organization and position of men and women can be traced to social rather than biological considerations. The universal association of women with young children and its various social, cultural, and psychological implications are seen as likely but not necessary (or desirable) outcomes, and they are more readily derived from organizational factors than from biology (p. 23 fn).

She suggests that the opposition of public and private/domestic is a useful structural framework for understanding the nature of women's social position and associated activities, as opposed to men's. Such comments have important ramifications for immigrant women, as they are united with other women by their biology[4] (as a woman).

Although this framework has been adopted by a number of writers in their work on immigrant women, there is a growing awareness that race and migration experience, and minority status play similar roles in shaping the subjective experiences of woman. These writers, who are predominantly visible minority feminists, are not underscoring gender inequalities (male domination and female subordination) in the home and in the larger society. Rather they are suggesting from their perspective that other social attributes such as race, ethnicity, minority, and immigrant should be considered in any study of visible minority and immigrant women.

---

[4] Biology is used in a broad sense here. It refers to the natural endowments of men and women. However, I would like to point out that the assumption, which seems universal, that all women have the ability to reproduce on the basis of their particular natural functions (woman's nature) does not consider those women of child bearing age who are unable to have children on account of infertility or congenital disability. This aspect of woman's biology is not universal; yet, it is implied within the concept of women's nature. I suggest that future writers need to address such differences as well as the similarities among women (and men) in order to break the universal misconception. For women who can not reproduce, their social life experiences are shaped by this factor, which are different from women who can. In societies where women gain status and power through their children (e.g., Asian and Middle-Eastern countries), those women who could not have children would not be able to negotiate their culturally ascribed subordinate position to one of prestige and power through their children. Moreover, barren women are generally stigmatized in all societies. In fact, I am not aware of a culture which values female infertility.

Many of their criticisms are directed toward the mainstream feminist movement which ignores the interrelationship of race, ethnicity, and class in its analyses of social relations between men and women and between women and women. They fail to show that immigrant women are oppressed and exploited in unique ways including by other women (see Szekely, 1990).[5] Ralston's (1988) perspective is that race, class, gender, ethnicity are social attributes which are defined and constructed in the historical and ongoing processes of social relationships, not individual attributes between immigrant groups and native-born Canadians (p. 65). Dua (1992) argues that the historical specificity of gender oppression for South Asian Canadian women is best understood by identifying the relationship between race, gender, and class in the lives of South Asian women in Canada (p. 9). According to Szekely (1990), we cannot assume the problems are ethnic in origin or residing in the person (see also Anderson, 1987). In addition, Liddle and Joshi (cited in Ralston, 1988)

> have also developed the thesis that the inferiority component of the gender ideology is a Western imported idea which is contrary to the Indian [South Asians] view of women as "too strong." Indian culture portrays women as strong, powerful and active and stresses the need for containment of this power (p. 80 fn).

This is in line with the new critique that Western feminist terminology is a product of white middle-class ideologies and experiences and cannot be generically applied to non-white cultures.

---

[5] Bannerji (cited in Szekely, 1990) claims that race and class are often an omission rather than that of commission with white feminists in their behaviour and attitudes toward visible minority and immigrant women. White feminists have been criticized for assuming their authority over minority women, for their patronizing attitude, for condoning discriminatory practices toward immigrant women in the job market and in their home and other similar kinds of common sense racism (pp. 132-133). See also an interview with Bannerji by Arun Mukherjee (1990) on how she perceives the concepts of multiculturalism and ethnicity in terms of being an immigrant woman and being a visible minority in Canada .

These and other writers have also suggested that immigrant women's subjective experiences are structured by dominant economic, social, and political elements that are outside the sphere of women's everyday lives, within the broader sociocultural context (see Anderson, 1987; Dua, 1992; Meleis, 1991; Ralston, 1988; Szekely, 1990). They argue that mainstream feminists, helping professionals, and social scientists often conceptualize minority and immigrant women's life situation as personal (the problem is with her) or cultural (the problem is with family traditions). Or else the source of her problems was perceived to be within the family. Hence, the solutions are in kind: to help the women to passively adapt to their life situations, by proposing that they go outside the family and immerse themselves into the Canadian way of life (Anderson, 1987:427; see also Szekely, 1990). Similarly, Nyakabwa and Harvey's (1990) article on Black immigrant women's adaptation to Canada found that:

> Physicians consider mental health problems to be merely a lack of adjustment, and they may not treat the immigrant woman properly. Her problems may be seen as individual rather than as a result of environmental pressure. Individualized solutions may then be applied, such as prescribing a tranquilizing drug, rather than helping her with language or employment difficulties (p. 142).

According to these scholars, the approach of the dominant health care system has exacerbated the physical and mental health problems of immigrant women. For example, if a woman was to follow the advice given, she might be in conflict with her family and own country-of-origin community for shirking her woman's role and responsibilities.[6] This was the experience of Anderson's (1987) study group of Indo-Canadian and Greek women when it discussed emotional distress or family stress with practitioners; these revelations then led the researcher to make the following statement:

---

[6] As a young child I witnessed the power of the collective on a young immigrant wife and mother. Being housebound and left on her own most of the time (her husband was either at work or gambling with other men), the woman decided to seek outside diversions. So she strapped her child to her back and went out to socialize with community members or to shop in department

> It would seem that some professionals had difficulties responding to the fact that even though the family might have been a source of stress, it was the only source of support women had; also, wihout the family a woman - whether Greek or Indo-Canadian - had no place in the ethnic community. Interventions considered to be appropriate in working with an Anglo-Canadian woman might be inappropriate for an Indo-Canadian or Greek woman (p. 427).

She remarks that health providers' (e.g., physicians, nurses, and others) inability to respond appropriately to the women's emotional feelings or family situation have been recognized by the women as indications of the limitations of professionals' competence. In light of this perception, the women, especially Indo-Canadians, often do not share their psychological burden with health professionals, thus severing their primary contact within the health care system. Without an understanding of the social problems - often the root of the physical problems - treatments are ineffectual, if not totally insensitive to the real needs of these women.

Immigrant women who migrate to North American societies are usually confronted at the outset by a tug of war between two sets of family values and attitudes. For example, recent immigrant women are expected to adapt their home culture's feminine roles and behaviours to those of the host culture without forsaking them.

(cont'd) stores. Her bold behaviour was brought to the attention of the husband by some of the Chinese community monitors. First, they disapproved of her traditional Chinese practice of carrying a child on her back outside the home, in the plain view of Canadians. Secondly, they frowned on her uncharacteristic Chinese female behaviour of walking the streets of Chinatown alone and with no other purpose then to talk with shopkeepers or strangers. The husband was very angry with the wife because her actions had led to a talk from his peers about her embarrassing misconduct in the Chinese community and his lack of control over his wife. The day after, she emerged from her apartment with a black eye and other signs of abuse. Subsequently, she remained at home. This is a good illustration of how community and family members make sure women stay within their culturally defined boundaries and roles.

The asymmetries in the social relations between men and women (Rosaldo's perceived near-universal opposition of the evaluation of the sexes) are strongly visible in both host and country-of-origin cultural systems. The task of having to balance the dominant and one's own ethnic group's cultural values concerning male and female roles was often reported by female immigrants to be a major part of establishing and orientating oneself and/or family to a new culture. Women have to transfer their home culture's gender myths to domestic life in the host culture.

However, the realities of domestic life in the new culture are different from those of the home culture. In agreeing to the husbands' decisions to emigrate, the women found they had little control over their lives (Ralston, 1988) because their family and female support networks were frequently left behind in the home country. In other words, when a woman immigrates her relationships and mutual support in the daily labour of housework and child care with female relatives and friends are broken. However, in the process of chain migration (relatives migrating later to the same geographic area in order to join those who are already there), some women are reunited with their mother and/ or sisters. But, the former pattern of support networks are more difficult to re-establish because of socioeconomic, geographic, culture, living and family arrangements, and other changes between the old lifestyle and the new lifestyle. Here are two examples of the lived realities of South Asian immigrant women:

> Example (1): The most difficult thing is that husbands are busy and the responsibility of raising the children is wholly on the mother. At home there are extended families, there are aunts and grandmothers helping to teach them religious values and their cultural values. Here, all this is on the mother (Ralston, 1988:69).

> Example (2): Taking care of all three children. Cooking and shopping and all. I think it was all on your head at once because there was no help. Back home you could get help. Your mother, servants, that kind of thing. You find yourself all alone when you come, doing everything . . . All of a sudden you are

> put in another culture with all the physical work with no social contact. Nobody talks to you (p. 70).

Similar views have been documented by other authors (e.g., Ng and Ramirez, 1981).

Women from ethnic groups found it hard to maintain and practice their religious beliefs. For example, South Asian women felt the loss of learning religious values from their female elders; something they would be doing as an important aspect of their culture if they had not immigrated. The place of religion in the lives of South Asian women is very important. This is borne out in that the majority of South Asians in Canada belong to four traditional religions: Buddhism, Hinduism, Islam, and Sikhism (Herberg, 1989:159). In the face of contradictions and confusion between old country and new country values, these women find solace in their religion. Similarly, the observance of important religious or folk celebrations among ethnic minority groups provides old country culture continuity, comfort, and ethnic identity. More importantly, celebrations and religious sessions allowed women opportunities to gather and socialize with others of the same ethnic and/or religious background. It is at these times that the stress and loneliness experienced by immigrant women is alleviated.

Religion is can be very important in the lives of ethnic minority immigrants. It plays a large role in shaping the immigrant experiences and perception of this population. However, religious diversity exists within some ethnocultural groups as well as between them. In addition, religious pattern among ethnic and racial groups changes over time for personal reasons, or a result of new country influences or old country's political impact on religious sects. For example, prior to the Second World War the majority of Chinese Canadians were either Buddhist or Confucian (p. 158). A tiny percentage of Chinese had no religious affiliation or were members of the United Church, Roman Catholic, or Presbyterian denominations. Since then, the proportion of Chinese Canadians who claimed to have no religion has risen over the years (Table 7.1, p. 149). Conversely, the number of Chinese Canadians who are Buddhists or Confucian decreased in proportion.

In recent years, immigrants of Chinese ancestry were primarily from Hong Kong. The growing number of immigrants who have lived under the Communist regime of mainland China is another reason for the current shift in religious pattern within the Chinese community, particularly the predominance of those with no religion (p. 158). The second largest group of Chinese Canadians has membership in various Christian religions. Religion is generally not a prominent factor in the studies of immigrant women.

In my view, all these factors are potential threats to the physical and mental well-being of many immigrant women.

> If married to a man who expects a clear sex-linked division of labour together with male authority, she may experience conflicts as she begins to accept Canadian values. If she begins to think that women's status is equal to men's or if she wants both husband and wife to share in domestic responsibilities, he may think she is showing disrespect for him. To question traditional values may create tension in families and lead to divorce, alcoholism, or wife abuse. Role changes brought about by children acting as gatekeepers [e.g., interpreters] . . . may also create family tensions (Nyakabwa and Harvey, 1990:144).

Moreover, the female role becomes even more conservative when traditional country-of-origin family norms are perceived by ethnic minority members as being threatened by the influence of Western ones (Danna, 1990).

On the other hand, when racial minority and immigrant women are reluctant to adopt Canadian values and/or overcome inequalities within the households (and in the labour market) in a process of social and personal transformation, they become stereotyped by white feminists as passive victims of family practices (Dua, 1992) or as uneducated, passive, hard to organize and politicize (Shin, 1992). Such racism, inherent in the feminist agenda, is viewed by Asian and South Asian feminists as evidence of white women's active support of the dominant culture's ideologies of race and class relations over non-white women.

A growing body of literature is attempting to dispel the myth that immigrant and non-white women are a homogeneous group. New research is stressing diversity within this populations of women. For example, immigrant women in Canada are bimodally distributed in occupational, educational, and income structures (see Boyd, 1990; Nyakabwa and Harvey, 1990; Ralston, 1988; Szekely, 1990). A sizable percentage of non-white immigrant women, especially Asian, South Asian, and South European women, can be found in well-paid, highly skilled and professional jobs, while an even larger percentage are employed in the lowest paid and status jobs such as service, food processing, accommodation and fabricating.

Knowledge of the host language is a big factor in determining the form of labour of immigrant women (Boyd, 1990:285). And, it is related to the birthplace of the women. For example, women born in both Asian and South European countries are least likely to know English or French. However, South European women have been found to be less well-educated than the Asian-born. According to Boyd, South Europe-born women are more likely to be unemployed and less likely to be in the labour force; and even when employed they tend to work in machining occupations and in manufacturing industries (p. 285). Asian-born women who do speak English or French are usually highly educated, and they are employed in high income white collar occupations or health and welfare industries (p. 288). On the other hand, Asian immigrant women who do not know one of the host languages are relegated to processing and fabrication industries as seamstresses.

One interesting finding is that very few immigrant women are working in between the high and low ends of the labour force (e.g., middle management, clerical, sales, and supervisory positions) (p. 285). Occupations of this type require working primarily in one of the host languages, and since the majority of immigrants born in Asia and Southern Europe do not know French or English well enough to carry a conversation, they would not be employed in this sector of the labour force. Boyd contends that there is a strong relationship between an immigrant woman's place of birth and her socioeconomic position in the host country (p. 285).

The source of the difficulties encountered by visible minority immigrant women in their every day life begins with the decision to emigrate. Many women emigrate to Canada as family class immigrants. This means that they are sponsored by husbands or other male relatives and under this sponsorship, according to Canadian immigration laws, they are considered as dependents (or second-class immigrants). As dependents, they are under the financial, social, and other types of support of the sponsors for as long as ten years (see Anderson, 1987; Ng and Ramirez, 1981). For a majority of women, especially women from lower socioeconomic class background, this length of time is unrealistic because their economic situation forces them to enter the labour market as soon as possible. Many of these women who did not work outside the home before they emigrated are now faced with the problem of balancing housework with paid work. Lacking language and marketable skills, they are pushed into the lowest strata of the labour market, a place known for its high rate of unemployment and lack of benefits. Women who have the language, skills, and high credentials, often experienced downward mobility. They find themselves in jobs which are well below their qualifications and training, and they occupy a lower socioeconomic status than in the home country. The problems faced by ethnic minority immigrant women in the labour force can be differentiated by the changes to their socioeconomic class positions in the new culture.

Under the double burden of paid and unpaid work, women, especially non-English speaking and unskilled women, have very little time to learn English or skill training. Such vehicles of escape from the lower echelons of the labour market are not even considered by most women because of the priority of financial security and family obligations - not even when English classes are available to them (Anderson, 1987). Although immigrant women have described the stress of having to juggle a double work day, their feelings of social isolation, loneliness, depression, extreme physical fatigue in the home, and pressures and discrimination in their work place; they perceived this as an integral part of their everyday reality as an immigrant and as a woman. Anderson states that:

> women's perception of themselves, and their families' perceptions of them, have to be taken into account. They and their families perceived a woman's responsibility as looking after the home; the man was 'breadwinner' whether or not he was actually in the workforce, it was not structured so as to allow them time to go to school. Women saw their priority as the family, and 'looking after' the family constituted the core of their activities . . . Furthermore, the length of time a woman had spent in Canada did not seem to make a difference to the way in which she described her life (pp. 421-422).

Women, therefore, see themselves according to the culturally derived ideology of woman's role or woman's duty which is embedded in dominant social institutions. This ideology has been reproduced by women in their everyday activities, trapping them in a life of despair. And as long as women sees housework as their duty or as a fact of life, the dominant ideology is perpetuated.

However, although the Greek and Indo-Canadian women speak of their hardships with the double burden of housework and working for pay and the conditions in the work place (all are in janitorial work) to Anderson, they nevertheless felt paid work has its positive side as well. They expressed confidence in their abilities as women, the ability to contribute to the family's financial situation, and the security of having money of their own. Anderson cautions that it is important that the distinction between the concepts of 'work for pay' and 'janitorial work' is clearly understood, not as social sciences define them but as they are defined by these women (p. 421). For many immigrant women, social assistance is seldom considered an option. And, as sponsored dependents they are ineligible for it.

Meleis's (1991) opinion is that inadequate attention has been paid to immigrant women's successful adaption to the new culture and roles. She proposes that both the stress and satisfaction experienced by these women in each of their role warrant examination (p. 374). The latter would reveal the benefits of living between two cultures. Also, some of the difficulties being experienced by women in the new culture may already have existed in their pre-migration experiences. In other words, we should also consider immigrant women's past personal and social histories prior to emigration as part of the theoretical framework. Pressure for immigrant women to adhere to the ideology of women's duty also comes from members of the homeculture communities and their extended families. Women have the major responsibility of preserving the traditional norms and beliefs of their ethnic heritage in the home. They are also expected to transmit their knowledge of the home culture to their children under the watchful eyes of their own ethnic communities and relatives. The special circumstances surrounding immigration (e.g., racial discrimination, broken family ties, the need to belong to a foreign culture) have forced individuals with no blood ties, but of the same or near same ethnic backgrounds, to claim kinship with each other. In the capacity of adopted kins, members of an ethnic group acquired the right to monitor recent immigrant women's conduct and actions. It is common for the women to have an abnormal number of visits by real and adopted kins to the home. Again, the country-of-origin community can be looked upon as a source of support and diversion for women who stay at home, but it can also be a source of stress because of the constant visits and the demands of the community.

Many immigrant women miss the social support network they had in their old countries: the sharing of child care and household chores within the same household or between households close to each other (see also p. 75). Personal problems with husbands or children can be confided to one's mother, sister, close friend, or neighbour. With emigration to Canada such close interpersonal relationships are broken. Other female family members are generally left behind. In cases where women have female extended family members living in the same household or city, they are able to maintain the some semblance of the old support. However, the stresses of resettlement in a new culture affect everyone, albeit in different ways, and these have an impact on the relationships between family members. Concomitantly, relationships between members of the same ethnic community in the host country are also different from those in the homeland. This is how a Greek woman describe the members of her ethnic community: "We are not together" (p. 423).

Women often have difficulties re-establishing the former system of social support because of lifestyle changes. For example, some women found themselves living with their husbands' families rather than with their own parents. Most of the Indo-Canadian women in Anderson's study lived in extended or nuclear families (p. 415). Extended or multifamily living is usually necessary for recent immigrant families for moral and/or financial reasons. However, once they have established themselves the multifamily group is changed to a nuclear family. Also, married women who have emigrated before, with, or after their own female family members (e.g., mothers, sisters, daughters) seldom lived in the same household or close enough to alleviate each other's family burdens and troubles. From her interviews with almost 300 Greek Nova Scotian women, Thomas (1988) discovered that a nonfamily baby sitter is a concept which exists outside Greek culture. In fact, there is no single term for *babysitter* , in the western sense, in modern Greek. Of the 162 Greek women who responded to the babysitting question, 86 said they never had anyone outside the family to babysit their children. This cultural practice then may mean that a woman who does not have older children to help out or close relatives around would be restricted in finding alternative modes of child care relief.

These changes reduce women's sources of support from their own female family members. For instance, it is easier for women to ask for help with child care or to discuss problems with mothers or sisters than with their own husbands' kinfolk, with friends of same ethnic background or with their own families, especially when they are the sources of distress. However, the reality for the majority of women is that social support networks to help alleviate some of the emotional problems are seldom available to them. Work schedule, geographical distance, and/or being busy with own family are some of the explanations why the women could not go to their mothers, sisters, and even female in-laws and friends for support. The women often complain that there is no one to whom they can turn with personal concerns, not even health care professionals, who generally do not have time to listen. The women find that health care professionals' attitudes and behaviour frequently reveal their covert ethnocentric biases and prejudice toward people who look different and who have a different culture-bound system of defining and explaining health and illness.

Christensen (1987), in her study of Chinese immigrants in Montreal, has outlined her group's pathway to support: All the immigrants in the study named immediate family members as the major source of support and a slight difference between the sexes in terms of the second source of support for personal or interpersonal problems. Women chose close friends, whereas men preferred other family members. [See previous discussion on Christensen's findings.] Members of ethnic communities and mainstream society were seldom considered for support with problems of personal or family nature. In general, Asian families preferred to keep serious personal/ interpersonal family problems within the immediate families or to themselves.

The study of elderly Korean immigrant women in America is a case in point. Although they have stressful life problems related to the negative consequences of migration, such as sociocultural stresses, and past experiences of hardships in the home country (e.g., problems with in-laws or husbands and the trauma of the Korean War), they do not like to confide to others their psychological problems because of a strong sense of shame, inadequacy, failure and misfortune (Pang, 1990:508). Psychological disturbances are viewed with fear, shame, and ridicule in most Asian cultures (see also Chan, 1979; Christensen, 1987; O'Sullivan et al., 1989). As a result, mental health agencies have very few Chinese clients. Within the Korean-American culture mental illness and psychotherapy are both associated with shame and stigma (Pang, 1990). Danna (1980) also found similar perceptions of psychological disorders in the working class Sicilian and Siculo-American communities she had studied:

> Generally, due to the dread of entrusting the care of an emotionally ill family member to impersonal doctors and agencies and also because of the stigma this type of illness places on the family, the member is cared for at home and is taken to a hospital as a last resort (p. 26).

Depression (Western medical definition) is virtually unheard of among Asian populations. Christensen (1987) points out that this may be due to differences in terminology and symptoms associated with it among cultures. For example, Korean female immigrants commonly self-diagnosed their emotional and physical distress in life as associated with *Hwabyung* - a Korean traditional and culture-specific folk illness related to suppressed anger provoked by such domestic problems as husbands' infidelity or conflicts with in-laws - to which was attributed a variety of somatic illnesses (e.g., gastric problems). But in the United States, the original illness model *Hwabyung* was modified by Korean immigrants to include an extensive range of emotions: sadness, depression, worry, anger, fright, and fear (p. 510). Thus the modified version of *Hwabyung* allows immigrant women to deal with their emotional distresses through descriptions of physical symptoms.

Anderson's (1987) study of immigrant women also mentioned that they were getting little help with their emotional distress. Anderson was surprised by this. The women were surrounded by members of their families and members of their ethnic communities. Many even visited health professionals frequently. This information seemed to contradict previous findings regarding immigrants, in which family members were said to be the primary support for personal and interpersonal problems. Anderson states that her data and Lynam's (cited in Anderson) correspond on one point in their individual research on immigrant women. Both were told by their subjects that they preferred not to share any personal experiences or experiences of members of the immediate family with members of their ethnic community. The women in Anderson's study felt that relationships within ethnic communities have changed - members of the communities do not feel close to each other. Therefore, the women were afraid of gossip or having their concerns judged according home culture values. Also, there is a hierarchical structure noted in the Greek community between recent arrivals and established members. In addition, they could not talk with family members because they were often the source of the problem. Nor could they talk with Canadians, due to the language barrier. They could not speak with health professionals because the latter are culturally different (p. 423). The women reported that they preferred to keep their personal worries to themselves. Surprisingly, they would share them with members outside of their ethnic community because they felt their problems would be kept confidentially with outsiders and also outsiders would perceive their problems in a different cultural context.

> When you are home (in Greece) you feel close to the people, but in Canada you do not feel close to the Greek people you meet . . . I would not attend a woman's group to talk about my feelings if they were all Greek. But if they were from different nationalities I would go and talk. The Greek people would probably make more out of what I said and they would tell others (p. 423).

Lynam (cited in Anderson, p. 424) notes that her sample of English speaking Canadian immigrant women gradually used more social support mechanisms. Initially, the women relied on their immediate family or extended relatives. Next, they went outside the family circle to members of their ethnic community. Finally, they progressed beyond their ethnic community to those support networks available in the wider Canadian sector.

Although the lack of English language skills is a major barrier to non-English speaking immigrant women, Anderson does not find this problem,

> an insurmountable one, and we should not dismiss this as the only difficulty in interpersonal relationships. For one thing, even though intepreter services might not always be available, it is not impossible for arrangments to be made for such services if a health professional sees it as a prerequisite to adequate health care. Also, although women were not fluent in English, some seemed able to carry on some type of communication with health professionals. This, however, might have been a time consuming process, and might have required a great deal of patience on the part of the health professional (p. 426).

One reservation I have about Anderson's view is that ethnic interpreters usually belong to the same ethnic community as the patients. As Anderson herself and Lynam found, immigrant women tend to avoid their ethnic community members when they have personal or family difficulties. This would prevent the women from speaking about personal matters. For many, physical complaints are manifestations of emotional distress created out of the circumstances of women's immigrant lives. In the presence of ethnic interpreters, female patients may not want to make their feelings of depression known. In turn, physicians can only treat those problems being communicated to them.

Secondly, I question the implication of Anderson's last sentence above. I agree that communicating through an interpreter is a time consuming process and requires patience on the part of the health professionals. Yet Anderson seems to be implying that their time is too valuable to be taken up with protracted communication. Unfortunately, Western medical practice is something like the conveyor belt system found in continuous process factories. Patients are quickly pushed through the consultation room and little time is spend on real conversation with the patients. Patience takes up time, a valuable commodity in advanced capitalist societies.

Meleis (1991) believes that many immigrant women, especially those of low income and with English language problems are high risks for all kinds of distress. Women, she says, who live between two cultures should be a concern for health care professionals

> because of the many roles they carry, some of which are invisible and unacknowledged, because of the work and energy they expend in attempting to make sense of two sets of cultural patterns that are very often opposites, or because they expend efforts in trying to make their values understood and accepted. They are at risk because of the differences betweeen their language and that of the dominant culture, because of the differences between the symbolic meanings in their interactions and the ways they interpret these interactions.

> They are at risk because they are confronted with many disappointments resulting from an emerging life trajectory that does not correspond with the cultural script they grew up with (p. 366).

The author then describes how Arab-American women learned that power and prestige are achieved by working hard and devoting themselves to raising the children, keeping the family together, and teaching the children their cultural heritage. In return, as they grow older, the children are expected to help their mothers attain the power base for which they have worked. However, immigration makes it difficult for some women to continue this female tradition, especially when the children become westernized. Consequently, according to Meleis, these women may be at high risk for mental, physical, and emotional health problems because of the changing cultural values and behaviour of their westernized children. Life transitions such as marriage, birth, menopause, and death within families are also often accompanied by a certain amount of distress because they change family relationships. These are natural and sociocultural factors which also have major influences on women's everyday life experiences and which may be the source of their mental health problems (see Meleis, 1991; Pang, 1990).

In traditional Korean culture, Korean women also expect respect and privilege in return for their sacrifices on behalf of the children in their golden years (see Pang, 1990). In old age as well as beyond (ancestor worship) they hope to be venerated by their children and subsequent generations. In a culture where only sons are considered important, Korean mothers often find themselves living with their daughters in their old age rather than with the eldest son as dictated by Korean traditional family custom. In addition, when a woman reaches her 60th birthday, she releases all her household responsibilites to her daughter-in-law. Yet, in the new culture, she is expected by both husbands and children to continue to do housework and to take care of the young grandchildren. For Korean women, these are the factors which cause their illness, *Hwabyung*.

Christensen (1987) found that Chinese respondents in her study perceived greater problems with their minority status experience (e.g., a feeling of not belonging, dominant language difficulties, feelings of being discriminated against, problems with immigration regulations, and difficulty accepting values of others) in Canada than with interpersonal problems (e.g., problems with marriage/love relationships, sex and authority figures). However, the health problems which have affected the well-being of immigrant women resident in Canada have seldom been addressed by health professionals in the wider community or within their own particular community.

Also, perceptions of problem areas by immigrants or visible minorities, whether they are health or financial, although individualistic or personal, are heavily influenced by culture (p. 191). For example, many Indo-Canadian perceive loneliness and depression as personal problems rather than as medical problems. Anderson's (1987) study groups of Indo-Canadian women had a different perception of what constitutes a health problem from health professionals. Mental health problems are usually defined as 'facts of life' by these women, and do not merit medical help. This is a common conflict between providers from the host culture and immigrants. The Greek women in Anderson's study, resolved this by either seeking out Greek doctors, or finding someone sensitive to their problems.

Regardless of language problems or contradictions in mental illness definition, argues Anderson, health professionals generally have difficulties responding to their ethnic minority patients' health concerns (which are essentially created out of social interactions between visible minority immigrant women and members of the dominant culture). They have continually prescribed solutions to their social-health problems which do not address real problems (see Anderson, 1987; Meleis, 1991) and may even exacerbate an already distressful situation.

On the other hand, health providers frequently complain about immigrants' misuse of the health care system. Immigrants either underuse or overuse it. However, as Meleis (1991) proposes:

> These behaviors may be redefined and reintegrated if viewed within the context of daily responsibilities of immigrant families and particularly in terms of the great demands on the time of low-income women. It is of interest to note that when clinics are appropriately staffed with bicultural and bilingual staff, immigrants tend to appropriately use even mental health services, which normally are least utilized (p. 371).

Women who work outside and in the home have very few opportunities or energy to seek out health care services. Wage loss, common in menial jobs for time off, and paid child care are two good reasons why low-income women underuse health services. Other barriers within health care structures which have deterred immigrant families from utilizing the health care system have already been discussed above.

Another difficulty for health care professionals is that immigrants' descriptions of their problems are too global or lack specificity so that they often have trouble diagnosing the complaints accurately and recommending the appropriate course of action. But Meleis (1991) opines that if a trusting relationship can be developed, women are able to present an accurate account of the situation, particularly through storytelling and dialogue - a result of the expansive and flowery nature of the Arabic language (pp. 371-372). But, again, such a time-consuming method of communication is alien to modern western health care practices. When practitioners convey impatience in their manner, Arab-American women tended to present their symptoms in a nebulous manner rather than take up their time. The end result is a feeling of confusion on the side of the professionals and a sense of frustration on the patient's side.

A second problem is that because health providers are more educated, Arab clients expect them to tell them what is the matter with them, not the other way around. A third factor, remarks Meleis, is the reluctance of Arab female clients to talk about private matters in the presence of a translator who is a male, a relative of the husband, or one of their relatives. Children as translators are also problematic. For example, what could be openly discussed in front of second sons could not be similarly discussed in the presence of the eldest sons. Health care workers need to be cognizant of these culture-specific social rules in order to deal effectively with the women's health situation. Other cultures evoked similar complaints from health care professionals. Educators and social service workers also have trouble in getting immigrant patients, parents, clients to comply to recommendations, advice, or requests. Noncompliance, suggests Meleis, if viewed from the standpoint of the immigrant's everyday experiences, may as well be compliance.

Anderson (1987) argues that the current health care system reflects the dominant cultural ideologies embedded within the social organizations and structures of the core society. Health professionals speak from their position within the health care system, and as experts legitimize the ideologies of the dominant society (p. 434). Thus the author recommends that professionals at least question the ideologies that underpin professional practice. She further advocates an educational program that trains future professionals to be reflexive rather than focusing on facts. Health professionals should have an awareness and understanding of the complex social and cultural factors that are at work in any patient-practitioner encounter (p. 435).

The matters discussed above illustrates the need for health professionals who are aware of the hidden ideologies of gender, class, race, ethnicity, and other forms of sociocultural relations which shape the subjective experiences of visible minority immigrant women. Social and medical problems must be accommodated in order to respond appropriately to these female patients. The issue of underuse among ethnic and racial minority immigrants can be resolved with culture sensitive and appropriate health care policies, programmes, and practices. In addition, the concept of diversity should be built into the dominant health care theories and professional practice. Mainstream feminist groups and social scientists also need to consider these issues.

I have argued from the standpoint that the migration process is at the heart of the majority of the emotional and physical distresses experienced by immigrant women, especially for women who are from a visible minority group, lack English language fluency, have little or no marketable skills, come from cultures dissimilar to the dominant culture, and are in lower income families. These are the women who require the most culture sensitive and appropriate health care policies and practices.

CHAPTER IV

ON BEING A VISIBLE MINORITY IMMIGRANT MOTHER WITH A DISABLED CHILD

The purpose of this chapter and the raison d'etre of this whole study, is to review studies that reveal the experiences and needs of a group of visible minority immigrant woman who are mothers to disabled children in Canada, as well as other western advanced capitalist countries. Reports and studies, primarily American, which have focused on white middle- or upper-class families with disabled children are also examined insofar as they contain implications for immigrant mothers. For example, parents themselves, specific disability advocacy groups, people with disabilities, and researchers have criticized the inadequacy and insensitivity of current government resources to meet the needs of handicapped people and their families. With increasing funding cuts, families and disabled people will have to fight harder to secure access to these limited resources. This has particularly bad implications for immigrant visible minority mothers and their families, especially those who have language difficulties, and may be too intimidated to verbalize their concerns. Mary (1986) comments that:

> The adjustment process of families of handicapped individuals takes place over time. The earlier this adjustment process begins in the lives of family members the less likely will be the "development of handicapped families around handicapped children". . . The more we know about what families are experiencing in this adjustment process and what resources are most critical to them, the more professionals may be able to effectively help families integrate their handicapped children into their world (p. 1).

Similarly, a knowledge of immigrant mothers' experiences and the resources they perceive to be important for themselves and their handicapped children will assist health and social policy builders to develop appropriate and viable policies and strategies. However, the resources should meet the needs of immigrant women in general and immigrant mothers of disabled children in particular without "forcing them to abandon their ethnic identitites and their countries of origin and without forcing them to integrate totally," says Meleis (1991:374).

Careful attention should be paid to the unique elements of the women's cultural heritage and their immigration experience, which affect their response to the disabled child and adjustment to the situation. For instance, Gupta (1990) observes that:

> As a socialist feminist, as a Black woman, I had no set ideas of the 'norm' which were [sic] upset by the birth of a disabled child. I felt no revulsion in the presence of disability. In fact, I had a solid framework for critically analysing the way in which the norm operated to exclude anything which threatened the conservative impulse of the status quo. That did not, of course, mean that I was totally immune to the way in which the culture of normality and super heroes is flaunted - like visiting the local health centre where a mother proudly puts down her eight-month-old child who walks confidently across the room as the mother informs all and sundry of the child's age, while I lower my two-year-old son to be weighed on the baby scales because he cannot sit or stand on the scales designed for his age group (p. 105).

Gupta felt that her 'sense of misfortune' and 'chest beating' (an Indianism, meaning to feel sorry for oneself) were somewhat eased by her feminism and racial minority position in Britain. From her perspective, she has always lived on the margins of the socially normal because of her politics (a social feminist) and physical attributes (a Black Asian). So that when presented with a third abnormal attribute of her life - disability (a cerebral palsied son) - she was able to react with less horror to this new form of aberration since she was never part of the conventional.

According to a number of writers (Begum, 1992; Chow, 1989; Moraga and Anzaldua (eds.), 1983; Mukherjee, 1990; Smith, 1983; Szekely, 1990; Vaid, 1989; Yee, 1987), visible minority or women of colour and other minority groups of women have been excluded or silenced within the mainstream feminist movement. These authors maintain that the mainstream feminist movement has done relatively little to advance the cause of visible minority and immigrant women. The assumption of homogeneous sisterhood within feminism legitimated white, middle-class, non-disabled, well-educated, and heterosexual women who spoke for women who could not claim any of these characteristics or attributes.

Smith (1983) argues that:

> Feminism is the political theory and practice to free *all* women: women of color, working-class women, poor women, physically challenged women, lesbians, old women, as well as white economically privileged heterosexual women. Anything less than this is not feminism, but merely female self-aggrandizement (p. 61).

Begum (1992) observes, as a visible minority disabled person, that the feminist movement has ignored the diversity among women, hence many women who have disabilities and who are black have been excluded from the feminist agenda (p. 82). Such narrow and homogenized perspectives have aided and enhanced cultural, racist, and gender misunderstandings and stereotypes.

Futhermore, Heath and Levin (1991), also proponents of the notion of diversity, suggest that people who plan early intervention policies, programmes and services need to recognize the cultural diversity of families of disabled children in order for these policies, programmes and services to be effective, successful, and viable:

> The consideration of culture is critical for appropriately designing and evaluating early intervention programmes serving disabled and at-risk infants and young children. *It has become obvious during the past 20 years that the programme needs of children in culturally diverse families are often not well understood by those who formulate and carry out social and educational public policy.* In addition, those children have historically received services of unequal kind and degree compared with those children whose families are by social class and culture part of the mainstream of a society . . . [emphasis is mine] (p. 67).

> In a multicultural society, people who plan policy, design programmes or provide service to disabled infants and toddlers cannot assume that their basic ideas about the meaning of disabling conditions and the meaning of intervention are shared by families served by these programmes (p. 68).

The above issues, which are only now being debated and addressed, have far reaching implications for visible minority immigrant mothers of children who have disabilities. If ethnic and racial minority women with disabilities and immigrant mothers of nondisabled children are experiencing difficulties with one or more of the factors - racism, handicappism, classism, sexism, and paternalism - that underlie the dominant ideologies of social organizations of the host community (i.e., within family structure, labour market, advocacy groups, and health care agencies), then visible minority immigrant mothers with disabled children are probably experiencing them too. The disabled children of ethnic minority immigrant mothers, in turn, may suffer from inappropriate and inadequate programs and services now and in the future.

Furthermore, being a mother of a disabled child who deviates from both the expected or normal of host and country-of-origin cultures places ethnic and racial minority and immigrant woman in a special group. Whereas Barile (1992) sees disabled women as an underclass within an underclass, where women within the disabled community are found at the bottom of the social class system in general and within the disabled population in particular, visible minority immigrant women with disabilities most likely occupy the lowest social position (below that of visible minority men with disabilities and white disabled women, respectively) in both dominant and ethnic minority communities (p. 32, and see also Begum, 1992; Dossa, 1990; McPherson, 1992). I argue that even within the disabled population, the people are not homogeneous but are likely composed of people of different physical and social characteristices and experiences. Present in the disability culture is a vertical racial, gender, and class infrastructure which mimics the suprastructure of the larger society. Begum (1992) points out that unlike men with disabilities, women with disabilities suffered from having to identify with two social roles - disability or female; both of which label disabled women as weak, passive, and inferior (p. 72). Disabled men, on the other hand, can choose to identify themselves with the negative role of disability, or with the dominant, powerful role of male. Besides the above two social roles, visible minority disabled women also have to carry a third one - 'racial minority;' one that the dominant group, which has the power and capacity, defines as inferior or subordinate. Barile gives a sense of the problems the disabled children of visible minority immigrant mothers have to face, especially female disabled children. Aside from Begum's article, no other work has examined the social problems of visible minority and immigrant women with disabilities.

However, two other Canadian femininst scholars, Barile (1990) and Dossa (1990), have published papers on the class and gender disparity between women with disabilities and men with disabilities and the nondisabled populations in general. All three authors argue, women with disabilities, all three authors argue, have been socially and economically relegated to the bottom of the ladder in both the disabled community and the larger nondisabled society. As women, their gender determines their low economic position and undervalued women's role. As disabled women, their disability and gender determines their bottom of the ladder economic position and asexual role. Women with disabilities are considered incapable of fulfilling even the inferior role as wives, mothers, and nurterers. Murphy, Scheer, Murphy, and Mack (1988) would say that they exist in a liminal state because, as in an initiation ritual, their identity has been taken away by society, but the difference is that society has failed to replace it with a new one that will reinstate them into society. To understand the exploitative and victimized situation of this group of women, we have to consider the ideologies which underlie Canada's capitalist system as well as its patriarchy.

The daily life of an ethnic minority immigrant mother with her handicapped child can only be understood from her own standpoint. One must, argues Meleis (1991),

> see the world through their eyes and obtain explanations that are provided by them as they see it and not substitute our explanations for theirs . . . (p. 374).
>
> It is important, then, to know how these women are thinking, how [we can] get at the meanings of their situations, and how to get at the wisdom they hold to help us in planning better health care for them (p. 375).

Moreover, one must take into account their experience with disability prior to immigration and the new experiences after their arrival into the new society.

We have stressed the profound implication of these works, with their various perspectives on disability, women and culture, on this particular study. Certain issues affecting mainstream disabled women and mothers with handicapped children can also apply to racial ethnic minority disabled women and immigrant ethnic minority mothers caring for children with disabilities. It is being suggested here that women, whether they are immigrants or host-country-born and whether they have disabilities or children with disabilities, share similar experiences with other women by the fact they are women (Anderson, 1987:418). However, the experiences of these women differ as the elements race, culture, and social class interact to shape the lives of visible minority women with disabilities (Begum, 1992:71) or with children who have handicapping conditions.[1]

Another position being proffered here, based on recent literature, is that these women are candidates for developing mental health problems (if they are not already experiencing poor mental health) because of the extraordinary stresses of caring for a child with disability while adapting to a completely different environment and culture. Women's poor mental health and other health problems are often the consequences of society's views of who should carry the main burden of caring for the disabled persons and where this care should take place. For example, the concept of normalization for handicapped persons is widely supported in Canada, the United States and other western advanced capitalist countries. Once people with disabilities, especially the mentally retarded, were segregated from mainstream society in large institutions, asylums, colonies, or training schools. Today as a result of the policy of normalization, the handicapped have been integrated into their own home or home communities (Ayer and Alaszewski, 1986; Brown, 1991; Marfo, 1991; Winzer et al., 1987).

---

[1] This idea of shared and unique realities between mainstream women and ethnic minority women with disabilities or parenting children with disabilities was not entirely mine but has been borrowed from Anderson (1987) and Begum (1992) and then modified to include the population of mothers with children who are disabled since they fit into it so neatly.

The ideology of normalization is that disabled people have the right to a normal and independent life and normal developmental experiences within the family and community (Winzer et al., 1987:13). Integration and the associated concept of normalization is based on the view of community care (Ayer and Alaszewski, 1986). Community care is defined as care within the community and the family. As a result, more and more newborn and young children with disabilities are remaining at home, and the parents are assuming the primary responsibility of caring for their every need. However, community care, a noninstitutional alternative to the care and education of special needs children, from a feminist view, is no more than care by mothers within the families. The authors, who had applied Oakley's feminist methodology in their examination of the division of caring duties within 120 households with mentally handicapped children in North Humberside, England, found (1986) that the mothers

> took the brunt of the physical care of their mentally handicapped child . . . [T]he community care of mentally handicapped children in [the] study was really care by women who received little additional support and assistance [from fathers and community]. It was, for most of the women . . . a life of hard work and social restriction (p. 254).

Ayer and Alaszewski remark also that the family model of care developed to replace the institution model promotes the view that care within a nuclear family provides a normal lifestyle for disabled children. The view of a nuclear family in community care is a traditional one: the father in the dominant economic role and the mother the carer of children and home. But it does not reflect the reality that women

> often have to earn a living outside the home and therefore they end up with a double role or burden as main carer and as wage earner. Caring for dependent people is often seen as 'second-rate' work that is accorded low status and low reward (p. 256).

Another problem within the nuclear family structure is that women care for their handicapped children alone or with minimal assistance. Needless to say this family model of care is underpinned by patriarchical ideologies of male role as breadwinner and female role as nurturer. This model of care is costly for women, especially those in the working class.

> Women, who have to provide the bulk of 'community care' experience two forms of cost which are easily overlooked, the loss of earnings which includes both actual losses and missed opportunities, and the emotional costs in terms of psychological well-being. Brown and Harris have shown in their study of depression that women, who care for dependent relatives, experience higher levels of morbidity than women who do not have that burden. It is possible that the long term costs of providing therapeutic and health care to these women may turn out to be greater than the short term savings (p. 256).

In addition to the mental and physical distress of caring for a handicapped child, there are difficulties derived from normal life stages. In a Canadian study of the mental health of women, Solberg (1989) notes that child-bearing and child-rearing are two of the critical developmental stages in a woman's life when her mental health is at risk because of her anxiety about motherhood and the well-being of the newborn. Lack of informal support networks, social isolation, and loneliness during post-partum are commonly faced by women and have been correlated with their degrees of depression. The 1984 Statistics Canada report calculated that 2 of every 6 women will receive treatment for a mental illness at some point in their life, while another source comments that post-partum depression for women may be as high as 80% (pp. 93, 102). These are revealing, if not alarming, figures and would most likely be much higher for the sub-population of mothers whose children have been born with a disability. This is the case in studies of mothers of chronically ill children in Norway (Storhaug, 1983; see also Hannam, 1988). They reported a high incidence of health problems.

In the past, and even today, the health care system has focused on the needs and care of disabled children, neglecting the fact that their well-being is closely tied to the well-being of the caregivers. If an immigrant mother's mental, physical and/or emotional well-being is at stake then this will in turn affect the quality of care to the disabled child. As wives and mothers, women have the primary parenting role, and the major responsibility for maintaining the health of the family. In her research on the health beliefs and practices of Palestinian-Americans in the Washington, D.C. metropolitan area, Maloof (1981) notes that:

> The role of the "wise women" remains very strong in the sense that female relatives or older, knowledgeable women in the community were consulted about health and child care. Women have traditionally had a major role in providing health care . . . [T]he principal person for using and dispensing "food-medicine" is the mother and that "special cures" are known as elderly female relatives. Within the study population family and social networks centering around women were found to be particularly effective in recommending physicians and in disseminating advice on childcare, family planning, lactation and child care (p. 73).

The notion of women as mothers and wives as health care providers lends strength to the belief that if a member family member is disabled or fallen ill, the mother is the most logical primary caregiver. In this sense, women as wise holders of health and child care knowledge have defined themselves and have had themselves defined by their particular culture as mothers and informal health providers.

Now I will focus on the following topics: (1) immigrant mothers' reactions to a child's disability; (2) immigrant mothers' perception of a child's disability and its cause; (3) support networks and utilization patterns. These topics will enhance our understanding of the experience and needs of visible minority immigrant mothers of disabled children. "It is important . . . to know how these women are thinking, how can we get at the meanings of their situations, and how to get at the wisdom they hold to help us in planning better health care for them" (Meleis, 1991:375). The main objective is to cause health care professionals, social scientists, feminists, social advocators, parents, and people with disabilities to think about this aspect of immigrant women's lives and respond to the questions raised throughout the thesis. It is important that the perspective of the mothers be the specific focus for all future examination. In other words, the goal is to see the world of caring for a disabled child through their eyes and, as Meleis (1991) urges, "to obtain explanations that are provided by them as they see it and not to substitute our explanations for theirs" (p. 374). As Mary (1986) noted, one should be aware that in existing literature on parental reactions to handicapped children, the majority of the data were collected from white middle-class populations, and may not apply to minority populations. Second, many of these studies omitted to describe the race or socioeconomic status of the subjects (see Buscaglia, 1983). Even when the ethnicity of the subjects has been made known, this is not often taken into consideration in the data analysis.

4.1 Immigrant Mothers' Reactions to a Child's Disability

The area that has received the most attention in North American family disability research is parental reactions to a child's disability. Findings reveal a fairly extensive list of common emotions felt by parents upon being told of the child's disability: ambivalence, anger, confusion, denial, depression, disappointment, grief, guilt, mourning, rejection, shock, suicidal impulses and others (Mary, 1986:3-4; see also Buscaglia, 1983). In her review of the literature, Mary points out that a number of writers have identified guilt as the most prevalent emotion among parents (p. 19). Their consensus is that such guilt arises because parents believe the birth of a child with impairments may be punishment for some transgression they have committed in the past. In other words, they feel responsible for the child's disability.

Grief/mourning and chronic sorrow are also frequent reactions of parents of handicapped children reported by Beddie and Osmond, Solnit and Stark, and Olshansky in the 1950s and 1960s (cited in Mary, pp. 19-22). The parents under observation generally experienced a sense of child loss (Beddie and Osmond), object loss (Solnit and Stark), or the loss of the fantasized child (Olshansky). Among Mary's three ethnic groups of women, 'love, grief and guilt' were the three common emotions in the first year following the child's initial diagnosis (p. 159). The families' ethnicity, SES, and the type and degree of severity of disability of the child were not factors in this case. Similarly, several studies looking at the relationships between mothers and their disabled children found that guilt was commonly expressed by these mothers (Shurka and Florian, 1983). Furthermore, the mothers in the same studies also expressed a sense of responsibility to the disabled child. Bromley and Blacher's (1989) interview sessions with 63 primary parents/ caregivers (58 mothers, 2 grandmothers, and 3 fathers) of severely disabled children about out-of-home placement decisions show that the majority of the parents had delayed placing their children because of guilt feelings and a strong sense of attachment to the child. However, although Bromley and Blacher's studied a mixture of ethnic parents - 74% White, 9% Black, 9% Hispanic, and 8% other - they did not consider the possible differential effects of culture and social class on parents' decision to delay placement.

Other investigators also report the strong sense of guilt felt by caregivers of children with varied disabilities. Guilt is a major source of stress, leading to mental health problems such as depression and decreased self-esteem. Some studies have also suggested that mothers with the extraordinary burden of a severely handicapped child neglect their own personal, social, and medical needs (Weiss, 1991). Subsequently, they are troubled by decreasing self-esteem and energy, and this in turn has an impact on the development and health of the handicapped child. Miller-Bank (1986) found from research on the relationship between mother's self-esteem and her acceptance of her handicapped child that the mothers who had participated in the study:

> expressed an enormous sense of guilt, concerned that they were in some way responsible for their child's handicap, as well as guilt for feeling disappointment in this baby by not having the baby they wished for and expected. For some mothers, this sense of guilt was overwhelming. It prohibited them from focusing on any appropriate aspect of child management or personal growth. The sense of guilt was so strong that at times it led to a state of anxiety close to panic, which immobilized them even greatly, and their level of self-esteem became almost non-existent (p. 86).

Mackeith (cited in Mary, 1986) goes one step further and suggests that each set of complexes of emotional reactions by a parent has a behavioural reciprocal (p. 21). For instance, "overprotection, rejection, depression, aggression, disbelief, withdrawal, and adaptation" (p. 21). Sometimes the behaviour manifested by the feeling may lead to serious consequences such as suicide or divorce. Divorce has been found to be three times and suicide twice as high among parents of mentally handicapped children as compared with the general populations. Reactions by the parents in Featherstone's group were sheer exhaustion and isolation (cited in Mary, pp. 21-22). She describes isolation as a special loneliness that only parents with disabled children can understand.

A correspondingly wide variety of models have been developed to understand the progression of family reactions to a handicapped child. The central notion underlying the models is that parents go through definite stages of reactions:

> the initial response to the child's diagnosis consists of shock, disbelief, anxiety, denial, and helplessness. This is followed by guilt, self-blame, depression, and a generalized grief reaction often including anticipatory mourning and/or chronic sorrow. . . There may be also an interval of searching for meaning, questioning reasons and values. . . This stage may be followed by anger. Finally the family comes to a point of chronic deterioration and disorganization or reintegration (p. 23).

These stages were patterned after Kubler-Ross's stage model for grieving for the dead and the dying (pp. 24-26). All the models were developed as a framework for health professionals and social workers to help them monitor parental reactions and to assist parents to accept the child's disability. However, more and more writers are questioning the validity and the underlying assumptions of the stage models. The focus below is on those criticisms that have relevance to my research.

Mary asserts that the universality of reactions suggested by the various staged models needs to be examined. As these models were generally derived from studies with white middle- and upper-class subjects, she felt they could not be extended to culturally different groups and other socioeconomic status groups. Moreover, the diagnosis of the child's disability also has an influence on the pattern of parental reactions. Unfortunately, care professionals and social workers alike have applied the stage models indiscriminatorily to families to help them work gradually towards the acceptance or adaptation to the child's disability.

Mary's study of mothers' reactions to their child's disability from three cultural groups reveals that white mothers were more likely to report having experienced definite stages of reactions than either Hispanic or Black mothers. Other subjects tended to speak of emotional reactions repeating themselves in cycles (p. 176). Usually these feelings reoccur at various developmental life stages, such as learning to walk and marriage.

Another revealing finding is the greater willingness of Caucasian women to talk about their feelings and child's disability than the two groups of ethnic women. The author, however, thinks it may be due to the fact that most of the white mothers had some form of college education, and may have heard about stage models in their academic courses. She observed the ethnically heterogeneous participants in the parent group called *Pilot Parents*, sponsored by the Harbor Regional Center in Los Angeles. The parents were predominantly Black, Hispanic and Caucasian in background, from upper middle- to upper-class, and had been educated beyond high school. Her own study had shown low participation among her non-white mothers in support groups, so she concludes that the ability or willingness to divulge personal feelings may have more to do with the parents' economic and educational level than differences in culture. Gupta's (1990) observation of her sole non-white presence in existing parent support groups for parents with cerebral palsy children supports Mary's findings of low participation from her Hispanic and Black mothers in parent organizations relating to various childhood developmental disorders.

Another critic of the universal application of stages of reactions theory by family psychotherapists and social workers is Patton (cited in Mary). He argues that while this may have been proven to be the case with Anglo-Americans as a group, it does not necessarily apply to ethnic minority parents (p. 25). In light of obvious cultural and linguistic differences between Anglo-American and ethnic minority parents, the latter would likely react differently to the disability.

Nancy Lim Lee's[2] (cited in Mary) study of 110 developmentally disabled Chinese children supports Patton's hypothesis about the importance of cultural and language differences in influencing parental reactions to a crisis situation (p. 25). She found evidence of stages of reactions among the study's Chinese parents and they appeared to proceed along the same sequence. Yet the

---

[2] The reference for Lee is missing in Mary's bibliography and the publication date which should have been beside Lee's name in the text is also missing. Attempts to trace the title of Lee's study were unsuccessful. It would have been an important source for the present study.

> nature of their reactions were different and the length of time in certain stages was longer than is normally expected. Influencing factors may be that the mother-in-law often blames the mother with resulting long-term guilt. Shame is strong in the Chinese culture, and families are sensitive to questions regarding family history and fearful of discovering something in the family background (p. 25).

Cultural differences were reported in Shigaki and Yim's[3] (cited in Mary) 1978 published work on the attitudes of 20 Japanese and Chinese parents toward their disabled children (p. 30). They suggested from their analysis of the data that the reactions of parents seemed to be more negative when the developmentally delayed child happened to be a male. This was related to the importance of sons in Asian cultures. In addition, the authors proposed that the cultural values of controlled social and behavioural conducts in these Asian cultures may have had a greater influence on parental feelings and their acceptance of the disability than the disability itself. That is, the social stigma of the child's deviant behaviour or appearance associated with his particular disability may be more of a concern for parents than the physical or mental anomaly because the actions of a family member reflect not only on the family but the community as well.

When Chan (1979) asked parents of Asian ancestry[4] about their primary concerns with their developmentally disabled children, he found that a majority of the more traditionally oriented respondents[5] expressed concern about their children's abnormal social skills. Chan's summation of these concerns is as follows:

---

[3] There is no reference for Shigaki and Yim in the bibliography also.

[4] The ethnicity of the participants were Chinese, Japanese, Korean, Filipino, Thai, Vietnamese, and Eurasian. The parents were either born in the United States or foreign-born.

[5] More traditionally oriented respondents are those who were identified by the author's 10 Items Cultural Orientation Scale to be more proficient in the native Asian language of their particular ethnic group, the primary language used within the household, close adherence to cultural practices, and higher contact with same ethnic ties (e.g., friends, ethnic media and literature) (Chan, 1979:44-46, 64, 151-153).

> Many parents indicated that their children often exhibited unpredictable, inappropriate social or emotional behavior in the presence of family friends or in public settings; in some cases, the children were "uncontrollably" aggressive or antisocial. Such behavior served as a source of persistent frustration and shame for the parents and other family members. Moreover, it further contributed to the public stigma already associated with the child's mental retardation. Again most parents of developmentally disabled children express similar concerns, particularly as the child grows older. However, more traditionally oriented Asian parents may have been particularly concerned about acting-out behavior in their children as a result of the high value placed upon emotional self-restraint and self-control (p. 71).

Additionally, parents of borderline or mildly retarded children often perceived the children's situation as a dual handicap. That is, the difficulties associated with the acculturation process among Asian immigrants are doubled if the child is also intellectually challenged. Moreover, parents are concerned that general society expects and demands more from this group of retarded individuals than the more severely retarded. This last concern has been similarly expressed by other families with handicapped children (see Ziolka, 1991).

Other difficulties besides cultural ones were also reported in the various studies with ethnic groups. Socioeconomic status, educational level, and severity of child disability have been suggested by Mary (1986) as possible influential factors in the attitudes and acceptance of the mothers of their disabled child. When she considered these factors in her data analysis there were noticeable differences between the mothers in terms of their ethnicity (Black, Hispanic or White), socioeconomic status (lower-, middle- or upper-class), and educational levels (little, moderate or highly educated) and the children's degree of disability (e.g., mild, moderate, and severe). Conversely, ethnicity was found to be of no significe among mothers parenting a child with the same degree of severity of handicapping conditions, in the same socioeconomic status, and of similar educational background. With the last two findings, Mary's study supports findings common in other studies.

However, her findings do not correspond to previous study results positing a strong correlation of high SES level, a more severe handicap, and unexpectedness of the disability (sudden disablement to a previously normal child because of an accident, illness, or other problems) with higher stress level and lower acceptance level of the child's disability. Mary found that it was the lower socioeconomic-scale and often single mothers of total care children who experience the higher level of depression, stress, anger, and isolation (p. 161). This is because low income mothers with severely handicapped children usually have fewer resources to help reduce or relieve them of the stress of their children's relentless care demands.

Using the questionnaire, *Attitudes Towards Disabled Persons* developed by Yuker and collaborators in 1960, Reiter, Mar'i, and Rosenberg (1986) interviewed Arab families from three different religious belief systems (Druse, Muslims, and Christians) in Israel on their attitudes toward their developmentally handicapped children and discovered a positive correlation between education and parental attitudes toward the disabled child. Although all three groups' parents showed generally positive attitudes towards their handicapped children, Christian Arab parents (who were mostly better educated) expressed less positive attitudes than the other two groups. On the other hand, Druse parents showed the most positive attitudes. The researchers' findings appear to contradict a parallel study (the same research problem and methodology) of Jewish Israeli parents, which showed more positive attitudes among better educated parents toward their children with developmental disabilities. Reiter et al. offer two explanations for their own findings:

> It appears then that the process of modernization, which effects a general drive towards improved status and at the same time the weakening of old traditions and a break in the structure of the family (Hamula), effects a certain negative attitude towards the disabled child, whom might be considered a hinderance to the upward mobility of the family.

> Another possible explanation to this finding is the difference between the belief systems of the three groups. The Druse, who believe in reincarnation and life after death, regard disability as a temporary or passing condition. Among the Muslims and Christians, 'disability' is regarded as a fatal misfortune or a punishment for a sinful act (p. 359).

We will consider here the significance of the first explanation. Reiter, et al.'s second point will be discussed later in this chapter. The process of immigration has been widely recognized as having a traumatic effect in numerous North American studies, particularly for those from villages and/ or developing countries. Many immigrants experience both positive and negative occupational, social, cultural, familial, and financial changes to themselves and their family. Old values and family ties are weakened. Moreover, the birth of a disabled child is also an unwanted event to families who are attempting to improve or maintain their socioeconomic status despite barriers from the dominant society and see this as an obstacle.

Beckman-Bell (1980) found a strong correlation between maternal distress and unusual and additional caregiving demands of handicapped infants. This is consistent with other studies (Erickson and Upshur, 1989; Gowen, Johnson-Martin, Goldman, and Appelbaum, 1989; Mullins, 1987). A second important aspect of Beckman-Bell's study is that families with financial problems also show significantly higher maternal stress. Alternative respite care and special equipment to help ease the burden are too costly for low income mothers. Beckman-Bell's study also shows that more severely handicapped children, less socially responsive children, more temperamental children, children who exhibit more frequent self-stimulatory behaviours, and more unusual and additional demands cause a higher level of stress for mothers. In essence, all these conditions have an impact on the mothers' reaction and acceptance of children with disabilities, particularly those with a disability associated with complications. Other scholars posit that the condition of community resources, family resources, a parent's own individual resources, past disability experiences, belief systems, perception of the disability, relationship between family members, and knowledge of a cause of the event have differing impacts on parental attitudes and reactions to their disabled children.

A majority of racial minority and immigrant women are of low socioeconomic position before immigration and remain in this position for a number of years. Even those from higher SES in their country of origin face downward mobility. For example, the majority of Asian American immigrant parents of handicapped children were disillusioned by their appalling immigrant situation (particularly those who were highly educated) and this feeling was heightened by inaccessibility and other barriers to mainstream special services for their disabled children.

> [They] express bitterness regarding the lifestyles and positions which they sacrificed in return for menial jobs and harsh living conditions in the United States. Underemployment and grossly inadequate family resources rapidly shatter earlier dreams of coming to America and succeeding in the "land of milk and honey" . . . While attempting to adjust to several radical transitions, these families have been unable to maintain continuity in the specialized services received by their children. Moreover, as is the case with many other non-English speaking immigrants, these children are often subject to indefinite waiting periods for services, and their needs remain unmet as a result of scarce bilingual resources among schools and generic service agencies (Chan,1979:156-157).

Some immigrant families with disabled children also experience family fragmentation. These families often enter the United States without their developmentally disabled children until they obtain waivers of excludability which gives them special legal entry rights. This may mean a separation of one years to three years from their children. These parents feel guilt for abandoning their child and for putting the burden on family members in the homeland. With Asian and immigrant families - and this may be true with other ethnic minority families - negative experiences in the new society may enhance parental feelings and behaviours toward the disability and the child.

Chan suggests that these factors are potential stress inducers for immigrant families, threatening their well-being and stability. Furthermore, the lack of resources for coping with personal and interpersonal problems caused by the birth/initial diagnosis of a disabled child resulted in marital difficulties leading to a higher rate of divorce among these families, suicide, alcoholism, depression, rejection of child, and even abuse. It appears that suicide and abuse (of women) are suffered by mothers and alcoholism with the fathers, but both parents face divorce, depression, and rejection of the disabled child (p. 157). Caring for children with disabling physical conditions places extraordinary demands on every member of the family, and it takes its toll on the marriages of parents across ethnic groups. Besides the emotional and psychosocial strains, there is also the strain on the physical and financial resources of the family. The latter is especially a problem with low income immigrant families because the presence of a disabled child in the family may prevent the mothers from working for a number of years. Also, the special needs of a disabled child are often costly.

In her paper based on an ethnographic study of the reactions of Mexican American parents toward their severely disabled child, Mardiros (1989) notes that all thirty-three parents (ten men and twenty-three women from twenty-five households) reported having feelings of intense grief at the moment of the child's diagnosis. Some expressed certain degrees of acceptance of the disability and the child. Her findings seem to conform to the general literature. However, the pathway to acceptance differs within this ethnic group and yet is similar to other ethnic groups. This will be discussed in the section on parental perceptions.

A common problem voiced by ethnic minority parents is the lack of information on the disability itself, the types of special therapy services and educational programs available, the prognosis, type of treatment and procedures, and how they can best help the child, and available support networks (see Chan, 1979). Similar concerns have been found with white parents (Ayer and Alaszewski, 1986; Buscaglia, 1983; Hannam, 1988; Pivato, 1991; Weiss, 1991; Ziolko, 1991). Often the anxiety felt by parents has been caused either by the lack of information or misinformation about the etiology and prognosis of the child's illness. The attitude of health professionals is yet another source of stress for parents. Despite good intentions, their behaviour sometimes made parents feel they are being blamed for the child's conditions; thus exacerbating the parents' stress (Weiss, 1991). This example suggests that the problem may be with the health care delivery system. However, one should not assume that language and cultural factors are unimportant, especially with immigrant and ethnic minority parents. Lack of or inadequate information may be due to communication difficulties between health care providers and non-English speaking immigrants.

The initial reactions of parents to their disabled child are similar. However, there are differences in the emotions felt by parents upon the child being diagnosed with handicapping conditions. The individual characteristics and resources of fathers and mothers have important effects on parental reactions. Diversity was found between ethnically homogeneous and heterogeneous groups, though cultural variations are not the only major factor in explaining differences in reaction patterns (stages or cycles) in cross-cultural studies. There is a need to examine the interplay between various factors: cultural, class, social, racial, educational, occupational, the type and severity of the childhood disability, previous disability experiences, familial relationships, coping resources (e.g., financial and support systems) and gender roles. For example, if the culture to which a parent belongs to is highly negative towards disabled people, then the parent will probably react to the news of the child's disability negatively because of the perceived stigma of society.

The class position of the parents and their reactions to disability seem to be linked. Middle and upper socioeconomic class had negative feelings while working class families were found to react less negatively (see Mary, 1986; Reiter et al., 1986). One explanation for the class differences in reaction is that parents of middle- and upper-class regard the presence of a disabled child as an obstacle to upward economic mobility (Reiter et al., 1986).

A number of studies looked at the factors of education and occupation to see what effect they have on service utilization (Mary, 1986). The result consistently shows that parents of low education and occupational levels persistently underuse health care services.

For immigrant mothers there is also the dimension of immigration process and minority status to consider. Mardiros (1989) aptly points out that to understand parents of children with disability we must first understand the attitude towards disability within a society. One might add that attitude towards disability within an ethnic minority community is also a relevant consideration with ethnic minority parents.

4.2 Immigrant Mothers' Perception of the Child's Disability and its Cause

A common view among parents of disabled children is that their own experiences have made them more tolerant of others who also deviate from the social norms of the larger society (see Buscaglia, 1983; Gupta, 1990; Mullins, 1987; Pivato, 1991). Gupta (1990) puts it well when she says that the common experience of social stigma faced by parents with children who have handicapping conditions breaks down the barriers we normally erect between ourselves (e.g, racial, social, political, economical, and cultural). Also, she felt that living under two social deviant categories - visible minority and feminism - prior to the birth of her cerebral palsied child have helped lessen the sense of misfortune (see p. 103 above). She reflects that feminism has given her the perspective to demand her partner share the responsibility of child care. This meant she could go out, but without the guilt which seems to consume other women with disabled children because their partners have to babysit. Perhaps other women who have a disabled child and who are identified as visible minority and/or immigrant may have the same outlook.[6] Feminism has also given her the voice to lobby for better services for herself and her disabled child and for other mothers with handicapped children. Through her feminist politics and her financially secure position she was able to have control of her life as a woman, a mother, and a person.

---

[6] Without investigation, I cannot make the generalization that other immigrant and visible minority women are feminists or see themselves as feminists. Feminism, however, is a vital aspect of Gupta's life, as well as racism and her privilege class position, and all have shaped her attitude towards disability.

However, Gupta's perceived common grounds with white women as a result of variable disability is elucidated by Goffman, who posits (1963) that "members of a particular stigma category will have a tendency to come together into small social groups whose members all derive from the category" (p. 23). Goffman is referring to people whom American society has deemed as social deviants and may fit one of three broad categories: (1) persons who are physically deformed and disabled, (2) individuals who are mentally retarded and disturbed, and (3) individuals who are ethnically, racially, and religiously different from a society's norms.

However, parent support networks were created for similar reasons. Giving birth to a child with a disability or caring for a child who is disabled for other reasons places parents into a category that is socially devalued. Thus, these families share society's treatment of them as devalued or defective. According to Weiss' study (1991), the degree to which a child's handicap is socially unacceptable to the public has been found to have an influence on the degree of parental stress and perception (p. 211). For example, families with an autistic child experienced greater devaluation and blame than families with children who have other types of disability. As Miller-Bank (1986) explains:

> Stigmatization is a universal phenomenon, culturally defined and culture bound. There is a vicarious victimization which occurs when persons associated with the stigmatized deviants are also stigmatized. The inference being that there must be something wrong with you if you are with that person. The parent of a handicapped child, possibly once a stigmatizer, is now stigmatized . . . [; and] these were the same parents who were just part of the general population prior to the birth of their child (p. 36).

My argument is that visible minority and immigrant mothers of handicapped children are stigmatized by society along with their disabled child. This then is added to their other stigmas - namely woman, immigrant, and visible minority. Their perception is every event related to the disability and the disabled child will be influenced by their various stigma categories which were created out of their continuous social relationships with the dominant group and the powerful ideologies of a patriarchical white capitalist society. The prevalent sense of guilt felt by parents with disabled children, apparent in virtually all cultural groups, may stem from a sense of having failed society by not producing a normal child. This feeling of guilt however is derived more from the social stigma attached to the disability than by the child's actual impediment (see Goffman, 1963).

Kojima (1977) notes that human reaction towards disability "never occurs without a complex sociocultural background [and discrimination and] prejudice is an acquired and emotionally colored attitude composed of hostility or favor to certain objects, persons or doctrines" (pp. 18-19). One can detect shades of Goffman in Kojima's statements.

Like ethnicity, gender, minority, immigrant, disability is yet another concept derived from the social interactions between disabled people and nondisabled people. Within this social relationship the concept of disabled people is defined and found short of the culturally accepted norm; hence, such people are devalued and placed in stigmatized categories already occupied by women, ethnic and racial minorities, immigrants (certain groups), and other deviants. According to Mardiros (1989): "People who deviate from the norm, those who look strange or behave oddly, arouse anxiety in any society, although each group will vary in the extent to which specific behaviors are judged to be deviant and a threat to the group" (p. 55).

In this respect, parent support organizations, each associated with a particular childhood disorder, can be perceived as formal social groups made up of parents belonging to the same social stigma category. Their purpose is generally to educate the public about the particular childhood disorder, to advocate for government services for handicapped persons and families, and to draw together parents with similar problems. Immigrant and refugee settlement centres can also be looked at in a similar manner. Most of all, with disability and all its associated problems, factors such as race and class may become less of an issue. However, existing parent support groups predominantly serve English-speaking, white, and middle- and upper-class parents. Ethnic and racial minority parents of handicapped children who do not speak English and poor parents in similar situations may find themselves barred from these groups (see Gupta, 1990; also Anderson, 1987 in Chapter III). Because of this problem and because of a lack of parallel parent support groups, this group of parents has no alternative support outside the immediate family and ethnic community. They would not be comforted by the knowledge that others in their situation experience similar emotions and responses.

The need for some kind of outside the family support systems may be a critical factor for the well-being and self-image of parents if extended family members (e.g., in-laws and other relatives) and close friends react negatively to the event by avoiding or blaming the parents rather than helping and supporting them. As immigrant mothers take on the primary caregiving responsibilities, they may be the most affected by the lack of practical and emotional support. A sense of alienation from friends and relatives because of the stigma of disability and the absence of a positive support system within the family or within the larger community has a profound effect on a mother's perception of her disabled child and the problems associated with the disability and herself as a mother. From the various studies cited in the present study, there is little doubt that positive support networks are very influential in terms of parental reaction and acceptance of the disabled child and own emotional and physical well-being. This is true regardless of the parents' economic and social standing. White parents often expressed deterioration of relationships with family and friends following the birth of a disabled child (see Erickson and Upshur, 1989). Immigrant women, especially recent immigrants, may have no or their small extended family and friend network prior to the birth of a child with disability. Immigration has fractured their larger support network in the home culture, especially female kins such as mothers and sisters, the most supportive with child care and other household activities. In the face of negative attitudes toward the child and parents by relatives, friends, neigbours, members of the ethnic and general communities, these mothers suffer from a lack of such vital informal support networks.

Negative attitudes toward persons with disabilities are common in many societies (Awaritefe, 1989; Couch, Goetz, and Baud, 1991; Kojima, 1977; Lagerkvist, 1992; Mba, 1983; Moyes, 1981; Pakrasi, Basumallik, Chowdhury, and Chakraborty, 1987; Tekle-Maimanot, Abebe, Forsgren, Gebre-Mariam, Heijbel, Holmgren, and Ekstedt, (1991)); and such attitudes are held by their families as well as the community. States Mba (1983):

> Many parents in the third world demonstrate negative attitudes towards their disabled children for reasons ranging from superstitious beliefs to family embarrassment. As a result, they hide their disabled children at home or send them to live with grandparents in the villages or farms (pp. 276-277).

Alternatively, parents of children with visible defects may limit their social interactions by withdrawing into their homes rather than facing inevitable public scrutiny and hostility (see Zoilko, 1991). Chan also commented on similar behaviours among Asian American parents rearing children with obvious visible abnormalities. This hiding the disabled child in the home, in his view, is partly attributed to Asian populations' historical experiences with discrimination and prejudice by the larger society.

In general disabled people through the centuries have been victims of social stigma, and those afflicted can become ostracised, abused, neglected, abandoned, or they become deified, symbols of good/bad omens, supernatural beings (see Burrow, 1977; Eberly, 1988; Kojima, 1977; Warkany, 1977). A common practice in some cultures is to destroy children with noticeable serious deformities immediately after birth. Infanticide[7] is

> a means of ridding a group of its weak and deformed children . . . The child was treated with benign neglect and allowed to die naturally, or the child was deliberately killed or abandoned. These were solutions to the problem of children who would not become full participants in the cultural group (Mardiros, 1989:67).

Some children with disability also died *in utero* or did not survive at birth. Persons with handicapping conditions were almost never considered just a variation of the human species, mere individual differences, in many cultures (Kojima, 1977). There had to be an explanation for their existence, and as well their annihilation.

Reiter, Mar'i, and Rosenberg (1986) cite the following reasons for the near universal rejection of disabled people:

> Evolutionary biology along with its sociological implications have led to the value of the 'perfection of man'. A person who is 'imperfect' deviates from that universally accepted value. Thus, the disabled person is unversally defined as different, and in most societies is rejected. This is the 'genetic reaction

---

[7] Mundurucu women in South America spoke of infanticide being practiced on infants born with serious physical deformities as well as illegitimate children and twins. In the latter case, this is due to the culture's belief that only animals can give multiple births. Children of multiple births are considered animals, not humans (Murphy and Murphy, 1985:192). Also among the Mardudjara people in Australia, Tonkinson (1978) reports that: "If the baby is deformed or otherwise visibly abnormal, if it comes too soon after an older sibling (that is, if the latter is still too small to walk long distances without being carried), or if the mother is in a weakened condition, the baby may be killed at birth by smothering in the sand. Women say that infanticide is only practiced when considered necessary, is uncommon, and must be done at the moment of birth lest the mother see the child's face or hear its cries and thus become so overwhelmed by compassion that she will not allow its death" (pp. 63-64). In the footnote below page 64, Tonkinson writes that: "Individuals who are, or who become, partly crippled, blind, or senile or who are later found to be deaf-mute or mentally deficient, are in no way ostracised or shunned, and only unmanageable, homicidally deranged persons would be put to death" (p. 64). The Mardudjara however disclaimed that such maniacs have ever existed within the group.

> practice' . . . Another universal source of rejection of the disabled is psychological: the disabled person ignites feelings of threat and anxiety among his/her surroundings . . . By the same 'rationale' the disabled are rejected also on aesthetic grounds . . . (p. 357).

Furthermore, the authors continue, they are rejected because of being considered a tragedy, a stigma and evil. As rejected people they share a minority status with other rejected people such as the Blacks.

Ethnic and racial minority parents' perceptions of their handicapped children's problems were explored by Chan (1979) with 58 Asian parents whose developmentally disabled children were clients of Los Angeles Regional Centers at the time of the study. All the families lived in an Asian area in Los Angeles. The parents reported having either recognized the child's abnormality at the time of the child's birth, later in infancy, or early on in school. Other parents were told by physicians or relatives about the child's problem. A few were informed by school teachers. Parents varied in their description of the child's type of retardation. Some were able to describe the child's condition with the specific medical label/diagnosis (e.g., cerebral palsy, Down's syndrome, epilepsy, and PKU). Others described the medical conditions rather than the medical label (e.g., brain damage from fever, a large head, and a dull look). Children with nonorganic, borderline to moderate levels of retardation were explained by their parents in the context of abnormal behaviour. Chan also found variation among Asian parents in their explanation for their child's developmental disorder. Probable causes were either explained in Western biomedical terms or through their own traditional cultural belief system. Of all the parents of Down's syndrome children, only three did not know its etiology; whereas the other parents could describe Down's syndrome as a result of chromosomol abnormality in the child and knew that the older the mother's age the higher the risk of her having a Down's syndrome child. The three who lacked information about the disorder were recent immigrants with little formal education and minimal interaction with physicians and other professionals. Other parents of children who were affected by prenatal infections, birth trauma, metabolic dysfunction, or neurological disease were well aware of the probable or undetermined causes. The same was found with parents whose children have Type II retardation but knew the causes are unknown.

Some parents believed their child's problem was caused by hereditary taint, spiritual or supernatural causes, and punishment for sins or moral transgressions (pp. 11-12, 70). These are the most common cultural beliefs regarding mental disorders noted in some Asian ethnic populations, and in other ethnic populations, such as Mexican Americans (Mardiros, 1989).

> One mother of two moderately retarded boys claimed that their "sickness" was caused from the "spirit of a dead horse" which had entered their bodies during her pregnancies. Another mother of three children, each of whom suffered from a form of familial-genetic retardation, claimed that her children's problems were related to her husband's "weak sperm" as well as her morbid thoughts and persistent fears of giving birth to a defective child during her successive pregnancies . . . A mother of a mildly retarded girl believed that her daughter had possibly inherited "bad genes" from a maternal uncle with a violent temper who, on one occasion, struck his wife and "knocked her eye out" (Chan, 1979:70).

One father also blamed his third child's cerebral palsy on his extramarital affair while his wife was pregnant.

Chan discovered that the perception of the child's problem and its cause, the concerns of parents about their disabled children varied according to the type of mental disorder. However, the various concerns correspond to those found among families with developmentally delayed children in general (i.e., how severely disabled children can learn self-help skills, the need for specialized medical care and supervision, and special education and vocational training to compensate for the deficit areas) (pp. 70-71). Two concerns have been mentioned above: the uncontrollable and inappropriate acting out behaviour of severely mentally retarded children and the 'dual handicap' of mild or borderline retarded children: adjustment to a new society and greater societal expectations than for severely handicapped children.

These concerns were expressed by parents who had a strong identification with their cultural heritage (more traditional cultural orientation). They were all foreign-born, had lived in the United States five years or less, and were traditional in cultural orientation which, Chan suggests, may account for their concern with the disabled children's embarrassing behaviour.

Some parents immigrated to the United States to obtain a medical 'cure' for their child's problem, overestimating American resources and technological advances in the areas of developmental disabilities. Although most parents were disappointed that the immediate 'cure' was beyond medical science, many were satisfied with the services for their disabled child. There was nonetheless disappointment that special health services and educational programs for their special needs children were not available immediately after arrival into the United States.

Other parents relied on traditional treatment practices. Chan illustrated this: A 60 year old mother who hoped to cure her son of seizure disorder claimed she performed daily, ritualistic prayer and meditation with her son and fasted intermittently for five years (p. 70). Another parent administered herbs weekly to his moderately retarded son even after coming to the United States despite no noticeable improvement in the son's intellectual capability (p. 73). One father decided to sent his retarded American-born daughter to Hong Kong for acupuncture treatments, hoping to 'cure her illness' (p. 73). When she returned a few years later, he discovered the treatment had not taken place and as a result she had regressed. Even then the father refused to seek professional help for the daughter. According to Chen's (cited in Chan) study this persistent reliance on traditional modes of treatment is typical of older Asian immigrants, and more noticeable with less educated Chinese men (p. 73).

Chan's findings provide some useful insights and may serve as a backdrop for this study regarding ethnic and racial minority Canadian immigrant women with disabled children. Of particular significance to the women here is the information discussed or mentioned by Asian American women, the majority of whom were recent immigrants. However, Chan did not attempt to differentiate between mothers' and fathers' perception of their disabled children. Only examples from individual cases show possible differences or similarities. The characteristics of the parents were described for demographic and comparative reasons but there was no attempt to consider their parental roles in the family.

The overall evidence showed that parental description of various mental disorders, their causes, parents' concerns, and treatment practices varied according to the type and severity of the child's disorder. It is also evident that personal or family characteristics such as educational level, socioeconomic status, membership status (i.e., immigrant/foreign-born vs native-born), length of time in the United States, westernized vs traditional worldview and cultural factors (e.g., mental disorder beliefs) influence Asian parents' interpretation, understanding and description of each of the areas investigated by Chan. The parents who were recent immigrants (e.g., Chinese, Indochinese, and Korean) tended to be working class with extremely limited financial resources. In fact, a two-parent working families are common among these groups of immigrants. Although many of the families whose children were clients of the CHLARC survived on poverty level incomes, few received public assistance through the Country's welfare program (p. 59). Such under use of social assistance is common among Asian groups. Working class Asian parents were found to have the most difficulties with the use of special services and programs.

However, two researchers (Shurka and Florian, 1983) conducted a study of comparison of the cultural differences between Jewish fathers' and mothers' and Arab fathers' and Arab mothers' perceptions of their disabled children. In addition, they also examined differences between Jewish and Arab parents. The Jewish (57) and Arab (74) sets of parents lived in northern Israel with their obviously physically disabled grown children (18-27 years of age). Shurka and Florian focused on three areas: (1) the amount of time and type of care required by the disabled child, (2) the parent-child relationship, and (3) the parents' perception of their disabled children's work capacities. The findings were: (1) no significant differences in any of the daily caring activities for the disabled children were found between Jewish fathers and mothers. However, the mothers felt the children required more help than did the fathers. Interculturally, Arab parents stated their children needed much care, whereas Jewish parents saw their children as requiring relatively less care. Interestingly, the severity of the disability of disabled children was not significantly different. (2) Arab mothers reported improvement in parent-child relationship since the injury and the fathers saw no significant difference. Jewish parents did not show any differences on this question. However, Arab parents reported improvement in their relationship with the child following his/her disablement, while the Jewish parents did not see any changes. A higher proportion of Arab than Jewish parents said that they spent more time with their disabled children than with the other children. Both Arab and Jewish fathers claimed decisions about the disabled children were not made in concert with the mothers, but both cultural groups of mothers declared they had some involvement with the decision making process. (3) Half of the Arab parents did not see their child as capable of work whereas most of the Jewish parents thought the child could do full-time or part-time work. No intracultural differences between mothers and fathers were detected on this work issue. However, the proportion of Jewish disabled children who saw themselves capable of full-time work was higher than Arab counterparts.

Intercultural and intracultural differences were found between two groups of parents with physically disabled children. For example, Arab parents tended to overprotect their disabled children more than Jewish parents. There was additional evidence of this overprotectiveness: the disabled child got more attention than the other siblings, received more care time, and had no independent decision making power, not being allowed to work, and having more interaction with the mothers. The implication is that it is the disability to which the Arab parents are attentive not the child. "It is possible that for the Arab parents the negative characteristics of physical disability are spread to all aspects of the disabled person, while for the Jewish parents this effect, although present, is less pronounced" (p. 373). A difficulty with this view is that Arab parents would not be receptive to vocational rehabilitation which trains disabled people for employment, and subsequently independence and self-reliance.

Another interesting aspect of the study is that the mothers' role in both cultures was distinctly more expressive (i.e., more time with the child or more positive relationship with the child) than the fathers' (i.e., decision-making) The investigators conclude that rehabilitation workers and other care professionals must be aware of the cultural aspects in the parents' perception of their child with a disability. In similar vein, Mary (1986) laments the lack of research on cultural factors influencing parental adaptation to handicapped children, and also the lack of cross-cultural studies on the feelings and reactions of parents of disabled children (p. 31).

Mardiros (1989) has things in common with Chan's study. She notes that Mexican American parents perceived their child's disability in two ways: as having a disability and as being healthy and normal (p. 57). All the parents knew the name of the child's primary disability (e.g., cerebral palsy). However, while some parents could describe the conditions associated with the medical label, other parents appeared to be confused by the medical characteristics of the disability. All the parents maintained that the medical label was only important for obtaining special services for the disabled child. They were more concerned to normalize the child's and their own lives. In addition, the parents had a good perception of their child's limitations and the severity of the disorder and its permanency and irreversibility.

According to the Mexican American parents, normality

> meant not having physical health problems such as those experienced by any child. Normal was described as maintaining activities of daily living at the present level without increasing restrictions on the child or parents. Normal included doing those things that approximate the activities of any child, such as having a library card and having a social life independent of

> the parents, focusing on the child's capabilities and interests, on what the child can accomplish, and not on what the child cannot do (p. 58).

To the parents each disabled child was an individual without peer, disabled or nondisabled. They did not believe any standard except the one derived from a child's overall condition should be used to measure that disabled child.

Furthermore, the parents clearly delineated disability and the normal child within.[8] "Illness and disease hold out hope for cure or for a decrease in the impairment, that is, a bettering of the condition, whereas disability has the prognosis of the impairment remaining the same, without improvement" (p. 58). Describing the child as being healthy places the child's problem into the realm of illness or disease, and thus, raises the parents' hope for a 'cure' (through science or physicians) or 'miracle' (through God) to happen with time. This is a hope maintained by parents despite their awareness that the physicians could do little for the disabled child. They themselves are responsible for looking after their handicapped child's well-being, communication skills, social interaction and basic self-care skills. Thus, the parents have shifted the child's disability, the physical condition, to a day-to-day management and promotion of the well-being of the child and family (p. 58). The parents thus adapted to the phenomenon and its associated problems.

Many studies of disabled children found that those with severe and multiple disabilities place extraordinary demands on parents. The constant care required by one of the Mexican American parents for her disabled teenage son corroborates the general findings:

> My son is not trainable. He's 19, a two-year-old in a man's body. He has to be fed; until seven years ago he had to be force fed food and drink. I have to take him to the bathroom, drop

---

[8] I see in this notion of "disability" as the "damaged physical body" and the "normal child within" as the "undamaged soul."

> his pants, wait till he goes, wipe him, dress him, bathe him at night, do everything. The only thing he really loves is his swing. I watch him. He finishes and walks to the door and waits for me to open it. That's as much as he can do (p. 58).

Interestingly, such pursuits were no different from those of some white British mothers in Ayer and Alaszewski's study (1986) of their severely mentally handicapped children.

Mardiros also says something about the parents' view of the cause of the child's disability. Two questions were posed to the parents. The question "What is the cause of the disability?" yielded answers from the participants from a biomedical framework (p. 59). The cause either came from a physician's explanation or they read about it in a book. In addition, the parents were able to provide information about the time the problem occurred, such as during the pregnancy, during birthing, or from birth up to a year. The other question "What do *you* think is the reason for your child's disability?" produced responses which Mardiros called sociocultural, or folk views. She found that all the parents held both views. Mardiros developed a typology of individual parental views.

In addition, Mardiros' analysis of the responses obtained from interviews with the parents shows that mothers' bad health habits and not those of the fathers were held to be responsible for the child's disability. Mexican American mothers often expressed anger about poor health habits during pregnancy and felt a sense of failure at producing an abnormal child. Parents who blamed medical interventions for their child's problems felt betrayed by the medical team. Subsequent contacts with health professionals were marred by this sense of betrayal.

A few of the mothers reported that physical abuse during pregnancy was the reason for the child's disability. However, abuse was mentioned only in the absence of the women's spouses. Abuse of their child by their father was also reported by some of the women. However, Mardiros observed that women who report child abuse tend not to report themselves as being abused.

These diverse views, explains Mardiros (1989), are the parents' way of trying to

> gain control over a situation that neither medical science nor the parents' culture could provide a satisfactory explanation for and why, in particular, it happened to them. The parent's perspective toward the disability was an important factor in responding to the disability and to treatment, and influenced the personal commitment of the parent to the child's therapy; whether help was sought or rejected, the level of involvement, the degree of follow-through on prescribed interventions, and the utilization of formal and informal support systems (p. 62).

She asserts the experiences of parents with handicapped children can only be understood from their folk model of disability and the child.

Mardiros found that the majority of the parents did not resign themselves to 'fate.' Five mothers in the study became active in working with other mothers in similar situations. Two mothers started support groups for Mexican American parents, two were active in advocating better services from the government, and one provided informal support to other parents in their neighbourhood. All but two of the ten fathers interviewed also became more involved with the care of the handicapped child. This is a departure from the traditional fathering role for which the Mexician men were prepared. Mardiros interprets this departure from the traditional parenting of the fathers as a positive personal growth out of the disability event (p. 66). In essense, a difficult situation can bring about changes in the asymmetrical gender relationships and roles in the home. In may still be asymmetric within the Mexican American families, but at least for the gap is narrowing. However, parents who had resigned themselves to fate were also reported in the study. These parents were found to be the least active in seeking informal and formal help for themselves and the disabled children. The data on the fathers are unusual when compared to other studies. Generally they generally found that most of the care of the disabled, as well as nondisabled, children was provided by the mothers whether or not she is employed outside the home. A second interesting aspect of the study is that the father who never accepted his child was a professional man with a yearly income of $50, 000 at the time of study. The remaining nine fathers were earning either $10-20,000 (5) or below $10,000 (4) annually. The evidence here is that economic class influences how fathers respond to their disabled children.

In her tri-cultural study of sixty mothers of young developmentally disabled children in two Los Angeles County Regional Centers for the Developmentally Disabled, Mary (1986) found that Hispanic mothers were more accepting of the child's disability and self-sacrificing in their role toward the child than Black and white mothers (p. 162). The mothers commonly remarked that the grandmother of the disabled child was more accepting of the child's diagnosis than the father. Both Hispanic and white fathers were found to have more difficulty accepting the diagnosis of the child than Black fathers. Although other studies she reviewed revealed that lower socioeconomic status parents were more accepting of the handicapped child than middle-class parents, her own work with Hispanic mothers did not support this. Both lower socioeconomic status and middle-class Hispanic women in her sample were very positive in their attitudes toward the child. The author suspects that the strong emphasis in the Hispanic culture towards the family and Roman Catholic religion influenced the views of the mothers toward the child and the disability. During her interviews with the mothers there was more family involvement with the child in the Hispanic families than the Black or white families. In fact, almost half of the husbands were around at the interview sessions, minding the children and listening to the interviews. In addition, some of the Hispanic women informed Mary that "no matter how disabled the child was, he was a human being, God's gift, to be nourished like any other of God's creation" (p. 162). This view appears to corroborate the Mexican American parents' sociocultural view of divine intervention outlined in Mardiros's causation schema.

Mary also found ethnic differences regarding the child's diagnosis. Differences in parental concern did not appear to be related to a lack of diagnosis of the disability or the severity of the handicap. Black mothers appeared the least worried about the lifelong limitations for their disabled children. Some of them perceived the child's diagnosis of non-specific delay, mild delay, or speech problems as no great concern; they suspected the children would catch up soon because the diagnosis didn't mean the children were retarded (p. 163).

In summary, parents' perceptions of the child's disability and its cause affect the choice of action or inaction towards this often stigmatizing, stressful, and highly emotional and demanding situation. Specific ethnic group or cross-cultural studies show the great influence of ethnic cultural factors on ethnic parents' perception of the disability. Mexican American parents have developed their own personal folk system to help them adapt the disabled child into their everyday lives. From a western viewpoint some of the remedies and practices taken by Asian or Hispanic parents may appear strange or puzzling, especially to alleviate problems such as seizures.

The common thread between these various ethnic families is the presence of a child with disability in the family. How they cope with, adapt to and accept the disabled child and their particular situation differ inter- and intraculturally from family to family and from parent to parent. Child (type and severity of disability), personal (level of education, temperament, gender), and family (middle-class status and ethnic heritage orientation) characteristics play major roles in the process of adaptation and perhaps eventual acceptance of the child.

Reiter et al. (1986) write that: "Attitudes towards the disabled are usually determined by two interdependent sets of independant (sic) variables; those which relate to the one who holds the attitudes (sex, sociocultural background, education, etc.); and those which relate to the level of disability (middle, moderate, severe)." Moreover, :

> While modern culture tends to understand disability as a scientific phenomenon, traditional cultures tend to perceive it as an act of fate. However regardless of the 'causal' perceptions, intracultural attitudes are not homogeneous. In

> Western society attitudes are positive, negative, or neutral, depending on class, religious belief, level of education etc. . . . Similarly, in traditional societies which tend to believe in fate, attitudes are not homogeneous.

Much of this has implications for immigrant and ethnic minority mothers with disabled children. Mothers of handicapped children are very likely to hold mixed views toward disabled people. Experience with the disabled child differs from mother to mother and between ethnic groups of mothers, just as their experience as an immigrant, minority, and woman is different from other women in Canadian society.

4.3 Support Networks and Utilization Patterns

There are two distinct kinds of support systems used by all parents with children with developmental disabilities: informal and formal. Informal support network comprises immediate and extended family members, friends, and neighbours. These people generally help by offering parents of handicapped children physical help (e.g., babysitting or financial aid) or emotional relief (e.g., listening to the parents or being sympathetic). Other informal support networks are churches and parent support organizations.

Although friends and relatives are capable of assisting with emotional, physical, social, and/or financial needs, they are usually less helpful in terms of giving parents concrete information about raising a handicapped child (Mary, 1986:40). This aspect is provided by the formal support systems, which are professional resources such as special education programs and schools, medical and social work services, and professionals working in these organizations.

One impression from the literature on immigrants and parents with handicapped children is that support networks, both formal and informal, are comprised largely of women. It is mainly women who offered their support to both women and men. I propose the view that support networks, especially nonformal ones, are essentially female institutions. In times of trouble, it is commonly the women relatives and friends who lend the most support, emotionally and practically. Men are seldom part of these networks. The predominance of women in the support role can be drawn from the discussion in the previous chapters regarding the cultural construction of male and female gender roles. The result is culturally legitimate gender asymmetry in which women are situated in a subordinate position to men. As the dominant sex, men assume the culturally valued role of breadwinner. Women are to occupy the culturally undervalued roles of nurturer and reproducer. The assumption is that women are by nature more suited to mother than men. Support networks then can be regarded of as an extension of women's nurturing role since the kind of support parents with disabled children asks for is primarily emotional support. The practical help parents need from supporters is that which is already performed by women, such as helping to care for the handicapped child or helping with the housework. It is from this theoretical perspective that we begin to understand the predominance of women, rather than men, in supporting families with disabled children (and to immigrant women). Support networks can be viewed as created out of patriarchy; out of women's need to support each other in their subordination and oppression.

Mary concludes that studies on support networks used by families of handicapped children commonly focused on formal support systems. Rarely do researchers investigate the informal support structures used by these families. Yet the value of social networks for this unique group of families is suggested by the studies' data. One of the reasons behind Mary's study is to rectify this oversight. In addition, she found that much empirical data were gathered from middle- to upper-class Anglo subjects; or the race of the subjects was generally not specified (thus ignoring culture-specific influences); and Black families were presented as if they were monolithic - they made up one percent of the sample populations, and lower-class and middle-class Black families were seldom studied together. However, some of the findings remain significant.

A few years earlier, Buscaglia (1983) also noticed the failure of researchers to describe the demographic characteristics (e.g., race, age, sex, education, socioeconomic status, and even the exact nature of the disability) of disabled, parent, and professional populations being studied. Often counselors were simply given their specific professional titles: therapist, counselor, or psychologist with little information about their individual characteristics or qualifications.

However, Mary (1986) comments that the literature from the 1950s onward shows changes of attitude of people with disabilities and their families and the role of social support networks.

> Attitudes about religion, the role of mother-in-law, grandparents, and the nuclear family have radically changed. Evidence since Faber's [1959] study suggests that extended family, friends, and neighbors play a positive role for parents of handicapped children" (p. 40).

The role of women in regard to disability has also changed over these years, and has been extended to add unpaid health carer to their primary nurturer and reproducer roles. With the eradication of instutions for the mentally retarded and severely disabled people and the favour of community responsibility and care for these people. Families have been assuming the responsibility of the well-being of their handicapped children. Even though, there is governmental compensation for the care (e.g., relief care allowance, special equipment, home modification) of individual with disabilities, the time and energy expended by parents as caregivers are far and above the compensation allocated. With continuing special program and service funding cuts, parents are also assuming more and more of the financial cost to meet the needs of their disabled children.

Mary's discussion of informal support systems pointed to three outcomes: (1) positive attitudes of extended families, friends, and neighbours were found to have a beneficial effect on the families. The value of social support networks is highlighted. (2) families, friends, and neighbours were very supportive through their assistance, concern, and acceptance of the child and family at the time of diagnosis, but these positive attitudes were found to vary over time. In other words, acceptance by the extended family tended to be quite variable as time progressed; some continued to be sympathetic and others were disapproving and unhelpful. (3) friends, relatives, and neighbours were an added source of stress to the families because of their negative attitudes (pp. 38-43). Grandparents denied the seriousness of their grandchild's condition (e.g., cerebral palsy), or overindulged, and were overly protective of the child. Close friends and neighbours were sometimes condescending towards the child and family. Such informal support networks were of little value to families as they contributed to the difficult situations rather than alleviated them. Social support networks are valuable to parents only when they can meet the particular needs of the parents, such as being able to give parents time out from the demands of caring for a child with chronical problems associated with the disability or emotional support.

Mary's tri-cultural survey also shows that although the Black families in the study had on average had the largest number of relatives living nearby, Hispanic mothers were even more relied on the family for personal needs. However, most of these mothers also mentioned the feeling of isolation because their spouse had denied their child's diagnosis. Mary also found that middle income mothers showed a higher degree of support in both expressive (e.g., emotional support) and technical needs (e.g., child care, transportation) than low and high income mothers.[9] Low income mothers reported the least support, mainly because of the inadequate resources of their relatives. High income mothers frequently lived the furthest from their parents.

Mothers with post-secondary schooling had a great deal more support than those with high school or lower education. Caucasian mothers generally were the most educated and occupied a significantly higher occupational level than Black and Hispanic mothers. Caucasian mothers received the greater overall expressive, technical support, and long-term family and friend support while Hispanic mothers received the least support in all fields. Single mothers reported less expressive and technical support from family and friends than married mothers. Support for mothers in all three groups commonly comes from female relatives or friends, and in the expressive area rather than technical areas. Members of the mothers' own family (e.g., mother, sister, and brother) gave the subjects the most support in expressive needs. For technical needs (e.g., transportation and child care), the female relatives (e.g., mother, sister-in-law, and sister) were the most supportive. Male relatives seldom provided any support.

---

[9] Mary (1986) defines expressive needs as "those aspects of the role of the parent of a handicapped child having to do with emotional needs eg. being able to express your feelings of frustration to someone; having someone give you moral support" (p. 17) and technical needs as those aspects of parenting a handicapped child such as "skills, information, tangible service eg. learning how to feed a child with cerebral palsy; getting assistance with child care" (p. 18).

Seventeen of the sixty mothers studied reported changes in their relationships with friends since the birth of the handicapped, and half said it was a negative change. These friends were hostile, rejecting, or uncomfortable in the presence of the child and/ parents (p. 116). Some mothers also indicated that they had more positive relationships with women who had experience with disability.

Mary also examined literature on parent organizations and the degree of involvement across cultural groups. Opinions varied on the significance of parent support groups to the lives of families of handicapped children and parental involvement in these organizations. Parents have been instrumental in the formation of support groups. They have also advocated and succeeded in obtaining public education and community services for handicapped people over the years. However, research findings are inconclusive about their efficacy as a support resource (p. 44).

Mothers of disabled children have often expressed the need to be with other parents who are in a similar situation, but only a fraction would participate in a parent group to researchers. One study (Lonsdale's, cited in Mary) reported some mothers said meetings were depressing. Some parents did not find that parent organizations helped them to cope with their disabled child. Furthermore, members of parent support groups were usually from middle- and upper middle-class, and this was cited as a possible deterrent for other parents from other social strata.

Mary's own study with Hispanic, Black, and white mothers of developmentally disabled children corroborates other studies reporting higher parent organization membership rate among white parents (pp. 167-168). She points out that white mothers expressed a need to talk about their problems with other parents more frequently than either Black or Hispanic mothers. Of the 17 Black subjects, 16 reported no parent group affiliation and 1 parent reported belonging to one parent group. Similarly, 18 out of 20 Hispanic mothers did not belong to any parent groups and 2 were members of one parent group. On the other hand, a majority of the Caucasian mothers belonged to one parent group, 12 (22) (Table 23, pp. 130, 128). This suggests ethnicity is significant. The type of needs met by parent and other (e.g., church) groups for the three ethnic groups of mothers were moral support, opportunity to talk to other parents, opportunity to escape isolation, specific information and facts, and specific service to the child (p. 126).

The author notes that mothers (across cultures) with little education, low status jobs, and low income level were the least likely to be involved in parent support groups. These mothers were not comfortable in these organizations nor did they think they are useful. Mary suggests that other factors such as transportation, time and child care may play a role in restricting the group membership rate of lower income mothers. The majority of parent support groups have regular and large gatherings and in a centrally located public site. These factors may be barriers to those parents who cannot leave their home easily, or are uncomfortable in large gatherings of strangers. Thus, according to Mary's findings, ethnicity and socioeconomic status are relevant factors affecting group membership rate among mothers of handicapped children.

Of the 60 mothers who participated in the study, 53 reported being a member of a church organization (p. 143). Half of them claimed to be Roman Catholic. The majority of these mothers reported they did not consider asking their church for help (pp. 178-

179). Many of the working class mothers revealed that the church was their primary social outlet; however, they have not been unable to go because of child care problems or no Sunday church programs for handicapped children. Mary expresses that church groups are another valuable source of support for families with handicapped children. She suggests that regional centers and other agencies who worked with disabled children and their families can do outreach with church organizations.

Professional services used by mothers of different cultural background were another aspect of her research. In general, mothers use professional resources for their handicapped children more than fathers. This might be related to mothers' primary caretaking role or the parental involvement model of the infant stimulation programs (Mary, 1986), also known as early intervention programs (Thorburn and Marfo,1990; Winzer et al., 1987). Some programs are delivered in the homes by a professional development therapist to help parents build skills to stimulate the motor and cognitive development of young children. Other programs take place in central sites with parent participation. Intervention specialists provide technical as well as expressive assistance to the parents. Mary (1986) comments that:

> Mothers of this study reported that these programs taught them how to teach their children and offered them help in dealing with their feelings about their offspring. Data on early childhood education shows that an approach to education which involves the parent may mean greater successes for both child and family. . . As parents learn to teach better they feel better about themselves as parents, their own abilities and their child's potential for growth. Thus, multiple needs - both expressive and technical - are met through the educational program (p. 171).

Half the parents from all three cultures support services that meet both their expressive and technical needs (p. 171). These were regional centers (based on a service delivery model to provide information on services and programs, counseling, crisis interventions, financial assistance, and to identify the needs of both handicapped child and family); physicians (to provide information about the child's conditions, referral to other specialists/ services, and listen and respond to parents' concerns and fears); and the stimulation/intervention service mentioned above (pp. 171-172).

One of the problems mentioned is the persistent underutilization of these formal resources by Hispanic, Asian, and Native parents of handicapped children. One study (Prieto-Bayard) cited by Mary reports that underutilization among Hispanic families was due to language barriers, mistrust of professional services, isolation, limited educational level, and strong familial and cultural ties to their Latin countries of origin (p. 49). The families' frequent visits back home have posed a problem to service delivery because of the disruptions they cause to the child's possible progress. Prieto-Bayard recommends that existing services develop outreach programs to increase service participation of Spanish-speaking families with handicapped children.

Another study (Atkins and Young, cited in Mary) identified several culturally based factors which impeded the success of intervention programs for physically handicapped children among Mexican American families: (1) strong family pride, which led to rejection of outside interference; (2) necessity for approval of a priest/other religious leader before accepting any treatment; (3) the machismo ethic - when male children's disruptive, maladaptive behaviour was often regarded as normal masculine behavior, thus parents did not perceive it as a problem which required professional intervention; (4) encouraged passivity in children, thus producing dependent behaviour; (5) lack of information about professional services for handicapped children; and (6) negative attitudes of extended family and friends (p. 50).

The commonly expressed problem of language as a barrier to the utilization of formal service organizations in existing literature led Mary to assume this would be the case with the Hispanic mothers in her study. But her findings did not support this view, despite the fact eleven of the twenty-one Hispanic mothers spoke very little English. This, she explains, may be a result of the frequent availability of bilingual staff in public schools and regional centers.

However, Anglo mothers with higher educational levels used more services than the other two ethnic groups.

Another ethnic difference was the extent to which parents are informed of services. Black and Anglo mothers were significantly more informed than Hispanic mothers, they differed in the type of information received. Black mothers were more informed about housing, welfare, and the school system and Anglo mothers were more informed about services, politics, recreational systems (reported by Giovannoni and Billingsley, cited in Mary, p. 52). Anglo parents were also more knowledgeable about potential services than Black and Hispanic parents.

Low income ethnic minority mothers used more public resources and services (e.g., regional centers) than private ones. The mothers reported that the needs most often met by professional providers were more technical than expressive. This corroborated previous findings. Secondly, these mothers felt that physicians were more concerned with the needs of the child than with the mother's emotional needs. Intracultural and intercultural differences appear to affect the type and use of formal support organizations among Black, Anglo, and Hispanic mothers.

Mardiros (1989) notes that Mexican American parents view formal support systems as a source of help with the biomedical causes of the child's disability. Formal support systems consist of professional resources such as specialized programs, institutions, services, and professionals, and access to them requires the disabled child to have a medical label. Like the Asian American immigrant parents with developmentally delayed children in Chan's aforementioned study (1979), the Mexican American parents also expected the physicians to 'fix' the child's problem, to make the child 'normal.' When the parents realized this was not possible they developed different expectations of the physicians: to treat the usual childhood illnesses, to treat any physical problems related to the disability, to provide referrals to other professionals, and to listen to what they are saying about their child. The latter was found to be an important point with the mothers.

In addition, the parents have specific expectations from each of the other professionals, such as community health nurse, teacher, physical therapist, and social worker. The informal support system was described as a source of moral support, material aid, and for parents to maintain a social identity, and information. The majority of Mexican American parents reported that the spouse, the wife's grandmother, the husband's mother, and elderly female neighbours were the most frequent sources of support.[10] The parents' church was also a source of aid. Some mothers commented on the positive changes in their husbands since the birth of the child. These husbands generally felt they were responsible for the child's disability because of past behaviours (e.g., going out with friends all the time). They belief that 'God' is punishing or testing them through the children. Through their Catholic faith, the parents were able to explain their children's disability. Subsequently, these fathers became very involved with the disabled children as well as the rest of the family (p. 66). The changes in the fathers for Mardiros' study show a positive personal growth through a difficult situation. However, one could not help but notice that it was the women who were the ones to lend support, not the men, with the exception of the husbands.

---

[10] I would like to clarify what seems a contradiction to my previous comments from other studies, and that is the lack of informal support for immigrant women from family members and friends in the new country. It is probable that the parents who had participated in Mardiros' study have their own parents living in the same geographic area as themselves, hence they were able to receive support from the female relatives. Secondly, female relations, especially mothers, have been found to be the most supportive. As I have explained before, several factors determined the amount and availability of sources of support from family members: work schedule, geographic distance, family responsibilies, and the degree of affection between the supporter and the supported. For recent immigrants, the need to establish new friendship ties may mean that this aspect of support would not be initially available, which is unfortunately also the time when immigrant women really need the support of friends. Those women who came to join or migrated at the same time with their parents or husbands' families may have an immediate source of support. Thirdly, women who do not know the host country's language will find themselves limited to the sources of support. Even if they don't want to turn to family or ethnic community members for personal reasons, they have no other support alternatives because of the language.

Notably, all informal supporters were of the same ethnicity as the parents. This has been consistently reported with other ethnic families with handicapped children. Another source of informal support for Mexican American parents was traditional Mexican healing practices. Differences in attitudes and meanings attached to folk interventions for the child's disability were noted by Mardiros with the Mexican American parents. For example, *remedios caseros*, home remedies, specific to normal childhood illnesses, were given to all the children in the family, whether disabled or not. If the disability was suspected to be caused by *mal de ojo*, *susto*, and *empacho* (Mexican illnesses), the disabled child might be treated with holy water and votive candles, olive oil, herbs, eggs, lemon, rice water, camomile, and anise tea. In one case a grandmother used egg white on the legs of her nonambulatory disabled grandson to help strengthen his leg muscles. Some parents, on the advice of their own parents, used curanderos (folk healers) to cure their child's impairment if they thought the causation was a *brujera* (hex by witchcraft). Mardiros (1989) maintains that "eliciting culturally relevant information from parents, that is, obtaining their folk model of childhood disability, is essential in promoting their well-being and the well-being of their child" (p. 67).

The most significant forms of informal support for many Asian North Americans with mental or physical health problems are the immediate family and extended family (see Anderson, 1987; Chan, 1979; Christensen, 1987; Meleis, 1991). Also important are ethnic institutions, which deal with various individual needs and problems, even emotional or psychological ones (Chan, 1979:12). "Families have . . . sought the help of "community caretakers" - that is, internal and informal resources (e.g., structures such as local churches, family associations, social and fraternal organizations, and individuals such as clergymen, physicians, lawyers, teachers, shopkeepers) which represent an extension of the traditional practice of collective responsibility" (p. 13). Correspondingly, many Asian families of handicapped children received both expressive and technical (see Mary's definitions above) help from extended families, friends, and ethnic informal structures. They have served as sources of referral and information for the parents as well as meeting their emotional and practical needs. Chan found that while a large proportion of Asian families (90.7%) were referred to specialized services by professionals (e.g., physicians and school teachers), the remainder (9.3%) were referred to these services by parents, friends, or relatives.

Okano and Woo (cited in Chan) reported that most Asian parents declared an interest in becoming involved in a parent group comprised of other Asian parents in similar situations (pp. 22-23). While they expressed occasional need for family counseling services, they were generally reluctant to seek out these services. Chan also reported that his participants favored a parent support network. Those parents who were never involved in a parent group expressed an interest in meeting other parents of handicapped children to lessen

> their sense of isolation within their immediate communities . . . Such findings suggest that earlier described cultural factors such as the "pride and shame principle" and the tendency to hide family problems from the public may be more prevelant [sic] among older generations of Asians and more applicable to cases of emotional or psychological disturbance in a given family member (p. 91, fn[3]).

Both Chan and Okano and Woo's study populations showed a similar desire to participate in parent groups, preferably ones of the same ethnicity. However, a much higher percentage of parents with family characteristics similar to those from corresponding country-of-origin emphasized this preference for a parent group of the same ethnicity (Chan, 1979:104). Additionally, all parents, who are characterized as more traditionally oriented (as measured by Chan's Cultural Orientation Scale) indicated a preference for ethnic service agencies and for same ethnic professional providers than their less traditionally oriented counterparts (pp. 44, 104). However, half of the latter group also indicated the same preference for both ethnic services and same ethnic providers.

Another difference between the two groups lay in the ethnic preferences corresponding to each specific professions (e.g., physician, teacher, CHLARC counselor) (pp. 114, and also 101-108). More traditionally oriented parents preferred that the professional be of their ethnic background. Several reasons for these preferences were given by both groups of parents. One frequently expressed reason is language difficulty. Non-English speaking parents, who were generally identified as more traditionally oriented, found it easier to communicate with a person who is able to speak their own Asian language. Second, some parents felt they would be more comfortable with a person who was familiar with the families' cultural background. Less traditionally oriented parents expressed their trust in the abilities of Asian professionals as well as their conscientiousness and dedication to their own ethnic group. A high percentage of the more traditionally oriented families in the study were in fact receiving care by same ethnic physicians. An interesting finding is that all the Japanese American families who were less traditional were cared for by physicians of the same background; whereas the Chinese and Koreans with ethnically similar physicians were more traditionally oriented.

Of the 40 respondents, 36 indicated immediate family members or relatives as their choice of potential caregivers (pp. 108-110, 114). However, most parents realized that certain factors may make it necessary to insitutionalize the child. One is the heavy financial commitment required to raise a handicapped child. The other is the child's disruptive behaviours on the designated caregiver's own family. Some parents, especially immigrants with no relatives in the United States, may have to send their child to their country of origin to live with a family member or relative. Out-of-home placement (i.e., institutions, group homes, foster parents) is not even considered by many of these parents. Chan states that his findings on this issue correspond to previous research reported for other ethnic minorities.

Secondly, Chan found that within this group of respondents the more traditional parents tended to favour personal resources rather than institutions. In fact, none of the more traditional parents considered institutionalization as an alternative form of care for their disabled children (p. 114). Again, this is compatible with findings reported by Okano and Woo (cited in Chan). Chan suggests that degree of acculturation may explain these cultural differences between more and less traditionally oriented parents. In other words, there is a positive correlation between increasing acculturation and increasing acceptance of institutional care of Asian parents with disabled children. As parents become more acculturated and less tradition, they might be more accepting of insitutional care rather than relying on immediate or extended family members (p. 109). Also, cross cultural studies show that Anglo parents with handicapped children reported a significantly greater preference for institutional placement. This evidence reveals intercultural and intracultural differences among families with handicapped children.

Other factors considered in the study were family and client characteristics. Among the Asian groups of families, Korean, Thai, and Vietnamese were found to be the more culturally oriented. In descending order, Filippino, Chinese, Japanese, and Eurasian families had less traditional cultural orientations.

When major demographic and clinical characteristics of Asian and non-Asian clients (child) were compared, Chan found no significant difference between the two groups, with the exception of level of retardation. A higher percentage of Asian clients were moderately retarded than non-Asian clients. Similarily, there were fewer Asian clients in the severe and profound and borderline to mild category than non-Asian clients. Chan points out that this does not support previous research results which indicated that proportionally Asian clients of mental health agencies were more severely disturbed than non-Asian clients (p. 50).

During Chan's research, he witnessed a significant increase of foreign-born and recent immigrant Asian handicapped children registering at the CHLARC (pp. 115-117). The number of Asian clients registered at the regional centre doubled over the previous year. According to the researcher, many of these clients and families was referred to the centre by ethnic service agencies (e.g., Asian Community Services Center, Asian Rehabilitation Services, and the Chinatown Service Center) located within the families' own ethnic communities. These ethnic agencies were staffed by bicultural and bilingual professionals who provided different kinds of service to people within the ethnic communities, including referrals. Chan attributed this dramatic increase in referrals to the rigorous outreach efforts of the CHLARC community worker who had personally contacted these agencies and other ethnic organizations to explain the nature of the center and its various services. Another positive outcome of the outreach programs was that such a referral network allowed CHLARC more access to the Asian populations who needed its services. This has changed the persistent underutilization of CHLARC services by Asian families.

The problem of underutilization of mental health services among various Asian American populations has been well-documented, but few researchers have focused on the use patterns of specialized services for the developmentally disabled by Asian families and their handicapped children. However, information from the small sample of studies demonstrates that Asian parents of disabled children are also underrepresented within the specialized service delivery systems. Ethnic identification, specific cultural characteristics, and socioeconomic class background of a family have been suggested as significant factors limiting the Asian family's use of specialized services. Similar factors have also been examined in various combinations for other ethnic and racial minority groups as well.

The religion of the parents has been considered in some of these studies (see for example Chan, 1979; Mardiros, 1989; Mary, 1986). Among Chan's sample group of Asian American parents, the majority claimed to be Catholic or Protestant. Slightly smaller in number were those who do not belong to a religion, followed by a small group who indicated they were Buddhists. The category "Other" religion appeared in Table 6.3 (p. 56) but Chan did not name the religions. Although Chan expounds on the influence of parental characteristics, such as cultural orientation, host language capability, education, occupation, birth place, age, family income, and length of residence in the United States, and the type of retardation of the child on the formal service and informal support utilization patterns of parents, he did not consider the role of religion in the lives of the parents. Another problem is that Chan failed to provide a breakdown of religion and ethnic and racial groups; they were all subsumed under the broad label Asian. However, since Filipino parents had participated in the study, it is probable that many of them were Roman Catholics. Similarly, on the basis of Herberg's (1990) comment that the majority of Asians of Chinese ancestry do not belong to a religion, there is a likelihood that the Chinese parents fit into this category.

Mardiros' (1989) Mexican American parents and Mary's Hispanic mothers who had been interviewed by the authors were largely members of the Roman Catholic religion. Mardiros' discusses in some detail the parents' Catholic faith and its influence on the process of parental acceptance and attitude towards disability and the disabled child. Mary's research study is similar to Chan's in that she had focused on the relationship between parental reaction and technical and expressive support utilization and the demographic characteristics of the parents such as education, family income, employment, age, ethnic identity, and language capability and the children's level of disability. However, her attempt to test the hypothesis that there is a link between a mother's strong religious affiliation and the belief that the birth of a disabled child is predestined or planned (sense of powerlessness) with the use or failure to use professional services to disbled children was not successful. Her theory was that mothers would score higher on the internal-external powerlessness scale if they believe in a predistined cause of illness rather than a random/chance explanation or cause of the child's disability. The hypothesis was unsupported for two reasons: (1) the relationship between the dichotomous "plan vs. chance" causal belief and "religiousity " was too linear for the complexities of the presumed dichotomous relationship. (2) "powerlessness" was too complex to measure with the I-E Scale and CPI-Locus of Control experimental instruments.[11]

---

[11] I-E Scale is the "internal-external control" scale by Neal and Seeman. CPI-Locus of Control developled by Alexander Tymchuck, M. Bansen, and M.

Though Black, Hispanic, and Asian families of disabled children all underutilize mental health and developmentally disabled services, Asian families were found to be the most underusing of the three. While many developmentally handicapped individuals from various ethnic communities are eligible for Regional Center services, the majority are not registered at the Center. Chan's respondents said that they knew of some ethnic families with disabled children who were not registered at the CHLARC. Subsequently twenty-one families were identified. However, it is possible these families were using alternative resources (e.g., traditional Asian treatments and practices) for their problems.

Underutilization is partly a result of a lack of information about existing agencies and their services, partly language, and institutional barriers among Asian populations. More traditional parents encountered a greater number of problems with language difficulties (pp. 96-101). Parents with inadequate English often had to rely on interpreters (e.g., relatives, friends, neighbours, or professionals) to translate for them. However, parents who needed bilingual interpreters often felt reluctant to ask these individuals for fear of imposition or inconvenience. Using bilingual interpreters often created miscommunication between parents and service specialists. Other parents who have some English have indicated their lack of confidence in asking questions or speaking about personal feelings and concerns to physicians and other professionals. In addition, these parents found it hard to fully understand what was being said to them. [I suspect a reason for this is that parents are usually unfamiliar with the jargon of the specialized professional. Undoubtedly, all parents faced this problem when speaking with professionals such as physicians.]

The second most frequently encountered problem by more traditionally oriented families was work schedule conflicts. Many working parents had problems taking time from work for appointments at the Regional Center. Sometimes the bilingual family

---

(cont'd) O'Connor at UCLA is the California Parental Inventory (Mary, 1986: 67-69).

employed. For example, all the women in the two-parent Korean and Filippino families of handicapped children were employed. The majority of these families were recent immigrants employed in poorly paid jobs. Transportation problems were also indicated by the parents, especially if they did not own a car or the only vehicle was used by the employed member of the family. Financial difficulties were often attributed to the slow reinbursement of CHLARC for various services contracted from private providers (e.g., physicians, homemakers, day care programs, board and care facilities and others) received by handicapped clients; and this has caused credit chasers to approach the families for payment. Lack of adequate information about available services, programs, and resources and legal restrictions required parents and the handicapped family member to separate while the former tried to obtain waivers of excludability before the handicapped child would be allowed to join the parent in the United States. The least problematic of all was babysitting or day care services. Many more traditionally oriented families tended to use immediate family members or close relatives to help with child care and seldom attempted to use outside sitters or day care facilities.

For the less traditional families, babysitting and day care services were frequent problems. Many had problems securing these private resources because very few individuals would take responsibility for a handicapped child; and the parents indicated their mistrust of these facilities and services even if they were readily available. Lack of information was a second major problem with this group of parents. A few parents also indicated work schedule conflicts, transportation problems, and financial difficulties. Thus, cultural orientation differences were attributed to differences in family characteristics. For example, bilingual interpreters were unnecessary since the majority of the less traditionally oriented families were English speakers while the other group of parents tended to be recent immigrants with minimal or no English language capabilities.

Although Chan's seminal study did not deal with male-female dynamics in terms of service utilization patterns and factors affecting type and frequency of services used by Asian fathers and mothers of handicapped children, it is nevertheless an invaluable study. However, as the majority of the 58 clients were living in two-parent households, the primary caregiving role was assumed by the mothers. Since the mothers were also participants in the study, it is plausible their responses would have an impact on the end results. This is most evident in the area of treatment, where the sex of the parents was given. In assuming woman's primary role as child carer across cultures, and through my familiarity with one of the Asian cultures, one which emphasizes women's domestic position and responsibilities, I would conjecture that it was the mothers who frequently met with specialized service agencies and its staff. By this reasoning, much of the information would have come from Asian mothers of handicapped children, because they would be most involved in meeting the needs of their disabled child, scheduling appointments, contacting services and professionals; and in seeking assistance from ethnic community service providers. Hence, Chan's research is invaluable for an understanding of the various special circumstances surrounding the lives of racial and ethnic minority and/or immigrant parents of developmentally disabled children, and possibly in the lives of visible minority immigrant mothers of disabled children.

The next piece of work provides confirmation of Begum (1992), Meleis (1991), Szekely (1990), and many women scholars' assertion that understanding of the actual situation of immigrant women's everyday lives come from listening to women speak about their lives. These women have not been given centre stage to tell their own story, and without more in-depth and gender and cultural sensitive research of their actual situation, the present health services industry will continue to be ineffectual for ethnic minority mothers with disabled children, and their families. We have failed to recognize the similar (compared to non-minority mothers) and yet different physical, emotional, and mental needs; social life experiences; feelings; creative and innovative caring behaviors and strengths of these women.

A rare find is the essay written by Gupta (1990) about her own experience as a Black Asian and feminist mother of a handicapped child in England. It is one of a collection of essays written by several feminists mothers about how they had accommodated motherhood into their feminist practice. Gupta's motherhood is a departure from the 'norm' because her child was born with damages to his brain. The uniqueness of her narration is that it was written by an ethnic minority and a mother of a disabled child in what Mullins (1987) terms "the most authentic [voice] among us, since [she] has actually lived the exceptional [life] and hard won [her] insights on parenting under extraordinary circumstances" (p. 30). The immediate striking aspect of Gupta's life story is that her reaction to the birth of a handicapped child and the problems she has encountered in raising a child with a handicap are very similar to those described by other parents, especially mothers, of handicapped children in autobiographies and empirical studies (see Pivato, 1991). However, her own ethnic identity, feminist principles, and other personal characteristices interacted with the disability situation to produce an experience different from the other families'. Her minority Asian heritage and feminism made it easier for her to accept those who deviate from the norm, and her class status has made it easier for her to cope without added financial worries and allowed her to lobby for improvement of services for people with disabilities.

Gupta also reports the positive effects of the parent group in a specialized treatment centre for children with cerebral palsy, where her handicapped son has been a client since he was four months old. Although it was an all white parent group she felt that their shared situations had made her and the other parents less conscious of racial differences. Because of the number of support networks she had found, she did not feel like joining a same-ethnic parent group unless the concerns of the groups became too ethnocentric. However, there were no support networks for Black Asian women with a disabled family member.

Another source of informal support came from people, predominantly young girls and women, who had volunteered to help her launch her programme of intensive physiotherapy which required two volunteers per hourly session for three hours a day. Thirty volunteers from local schools, student nurses, pensioners and single women came into the home to work with her son. She was amazed at the enthusiasm and energy of these people, whom she had not known before, and some good friendships were formed. Another beneficial change was the greater involvement of her partner with their son, though she still assumed the lion share of the caregiving burden. Other support resources she tried to obtain were nursery school and respite care, but they were either were not readily available, or else the quality of care was suspect.

Gupta's essay about her life with a severely disabled child illustrates how an ethnic minority, and feminist, mother reacts to her disabled child and herself as a mother and the corresponding types of informal and formal support networks. To cope with her emotional trauma she had read widely on cerebral palsy and to ameliorate a sense of guilt she assumed the responsibility of giving "birth to him again, to deliver him from his body as much as possible through physiotherapy and educational input" (p. 100). These feelings, perceptions, and behaviours are similar to those experienced by other parents of handicapped children, such as Mardiros' Mexican American parents and parents in the other studies cited above.

4.4 Caring Mothers and Mothers as Caregivers

The complex problems encountered in the everyday experiences of ethnic immigrant mothers with their disabled children and with the health care system are mainly attributed to society's attitudes toward disability.

> Society creates handicaps. While most disabilities are products of birth or accident, the debilitating impact on the person's life often results not so much from the "disability" as from the manner in which others define or treat the person (cited in Buscaglia, 1983:11).

Although an individual's actions are limited by his/her particular disability, it is society which turns that person's actual disability into real handicaps. Theoretically, disability can be defined in two ways: (1) clinical or medical, purely on the etiology of the impairment and (2) as a cultural construct, which focuses on the interactions or relationships between disabled and non-disabled individuals in their everyday social life.

The current movement to have families act as informal caregivers for individuals with disabilities at home means that family members rather than the health care system are gradually taking on the bulk of the medical responsibilities. Mothers often have the prime responsibility of child-rearing in the family, especially with disabled children (Miller-Bank, 1986). In such cases, the majority of immigrant ethnic minority mothers with handicapped children suffer the hardship and stress of a double work day. In many respects non-immigrant women face similar constraints of outside work and house work and child care. Entry into wage-labour for a large number of immigrant women, especially from Third World countries, is a departure from the cultural norm of their former countries, where women stayed at home to raise children and look after the home.

My other point is that ethnic minority and immigrant mothers share similar experiences with other ethnic minority and immigrant women with or without nondisabled children. The loneliness; social isolation; depression; racist, sexist and class discrimination; and for many the heavy burden of double days at paid and domestic work are feelings commonly expressed by immigrant women, especially recent immigrants who lack English language skills and low income women (Anderson, 1987; Boyd, 1990; Dua, 1992; Ng and Ramirez, 1981; Ralston, 1988; Szekely, 1990; Thomas, 1988; and many others).

How do visible minority mothers who are also immigrants come to terms with the knowledge that her child has severe handicapping conditions? Whether the conditions occur at birth or later in life, parents' initial reaction to the tragic news is much the same: shock, anger, denial, depression, grief, and sorrow. Culturally and racially different, visible minority mothers and non-visible minority mothers share similar initial reactions to the news their child is disabled. The ensuing primary responsibility of caring for a severely disabled child is virtually no different for the two groups of women. Women are still found in the role of nurturer today. Concomitantly, women continue to do all the housework with little help from other members of the family.

From their review of the literature, Erickson and Upshur (1989) reported that in general most families' fathers have little involvement with caretaking activities.

> Fathers in two-parent families typically spend about one-third as much time with young children as do mothers, although over the past decade evidence points to a slight average increase in the quantity of paternal involvement. Even more significant, on average fathers spend only about one-quarter as much time in one-to-one endeavors with young children. In two-parent families, relatively few men take on an equitable share of the day-to-day responsibilities involved in child rearing (Biller, 1993:9).

In contrast, according to Erickson and Upshur (1989), some fathers of children with disabilities become very involved with caretaking tasks but only with boys. Another study found no difference in the rate of involvement between fathers of disabled children and fathers of nondisabled children. Ayer and Alaszewski's (1986) results from their study sample of mothers show that fathers will occasionally watch the child with the disability at home, whether the father is employed or unemployed. Yet, they were more willing to take care of the children with no disabilities (e.g., babysit).

Whether in their country of origin or in North America, immigrant women are responsible for both child care and housework, and even full time work outside the home. The major difference is that in her old country, an immigrant woman has a network of female relatives and friends to share the work, but this social support network is broken when she immigrates to the new country and has to do everything alone. In their seminal study of the everyday activities of immigrant women within the home in Canada, Ng and Ramirez (1981) found that the fathers have little or no involvement with household chores and child care - overburdened mothers and inadequate involvement of fathers syndrome (see Biller, 1993).

Generally, the husbands are involved with financial decisions, such as buying major items for the home. This is supported by existing literature (see Anderson, 1987; Ralston, 1988; Thomas, 1988; and studies on immigrant women). A survey of the literature reveals the double burden-double day for the majority of immigrant women visible or nonvisible. The addition of unusual caretaking demands for children with disabilities on immigrant women would mean a triple burden-triple day.

Women of the wider Canadian or American community may be better off because they tend to have their extended family (e.g., parents/in-laws) and friends living in the same geographic region as themselves. Yet, the major burden of rearing a child with disabilities, especially a child who has severe medical problems or is severely delayed in his/her motor development, usually means frequent difficult and atypical caretaking responsibilities (e.g., tube feeding, or seizure monitoring) rests on the shoulders of mothers (see Ayer and Alaszewski, 1986; Erickson and Upshur, 1989). The rounds of therapeutic sessions, medical appointments, medication, and simple basic activities such as feeding, clothing, cleaning, and bathing are continuous and time-consuming work, frequently leaving women exhausted and with no time for anything or anyone else (see Ayer and Alaszewski, 1986; Erickson and Upshur, 1989; Hallsted, 1988).

A study by Breslau cited in Erickson and Upshur (1989) found that mothers of 3 to 8 year-old children with disabilities (e.g., cystic fibrosis, cerebral palsy, myelodysplasia, and multiple physical handicaps) spent more time on household tasks than mothers of children without disabilities. In addition, the mothers of disabled children spent an average of 4 hours per week (in addition to household tasks) administering home therapy. For the mothers, the unusual and additional demands made on them may not diminish with time, to contrast to those of mothers of nondisabled children. They will face, in the case of female children, the added task of a menstruating teenager and adult.

Many mothers of handicapped children in the literature commonly express the emotional, psychological, and physical strains of rearing a child with a disability. Ayer and Alaszewski (1986) found many of the English mothers in their sample suffered from lower back pain on account of having to constantly lift their adolescent children in and out of bathtubs. Because of the children's frequent incontinency, most mothers found it easier to bathe them, but this required a great deal of lifting. Low self-esteem and stress are two of the many psychological problems women with disabled children experience as a result of their particular situation (see Beckman-Bell, 1980; Miller-Bank, 1986). After discovery of the disability, for the early period at least, all parents are united in the revelation that their children have been diagnosed as disabled. All parents will agree with what Buscaglia (1983) says:

> Giving birth to a disabled child happens quickly. There is no forewarning, no time for preparation. Educational or psychological counseling at this crucial time for . . . confused parents is almost nonexistent, either in or out of the hospital. So much of what they will do for their children must come from instinct, or trial and error. As to their feelings, their fears, their anxieties, their confusions, their despairs, they will have to handle them as best they can (p. 25).

All in all it is not an easy task for parents when "[s]ocial systems are built upon the potentialities of the average individual. These potentialities should assure that all functions within society will be filled, even if at a mediocre level, so that the group will survive" (Mardiros, 1989:55). Parents of children with disabilities, however, have great difficulties meeting the responsibilities of transmitting cultural norms so that a disabled child behaves in accordance with the norms of their social group. The cultural tradition which helps to guide parents in rearing their nondisabled children is lacking for parents with disabled children. Even disadvantaged children (e.g., Black American, Mexican American, and Native American) are raised within a rich cultural tradition (Mardiros, 1989). Gupta's (1990) sentiment is that she could not bring herself to think of developing a positive identity and culture for her cerebral palsied child as a Black person or making him sensitive to socialist and non-patriarchal values when such things as expressing his basic needs (such as hunger, pain, joy) may require years of work (p. 99).

In both Canada and the United States, the growing trend is for families to assume the primary responsibility of caring for individuals with disabilities at home. The current trends are toward home care and community integration, not isolation and segregation. The humanist approach and modern health system means that parents with children who have disabilities are taking on more responsibility in meeting the special and normal developmental needs of these children. Few parents are prepared for the complex medical problems of the child, and often expect to learn them in a matter of days (Buscaglia, 1983). As Miller-Bank (1986) points out in her study on the relationship between mother's self-esteem and support resources to her acceptance of her disabled child, most often the primary caregiving responsibility, even with a normal infant, becomes the mother's.

Buscaglia (1983), Miller-Bank (1986), and a number of others have remarked on the covert expectations of the medical system that mothers (and fathers) of disabled children will instantly become experts in their children's needs and obtain appropriate medical, educational, and remediation programs and treatments for them. Literature on parenting children with disabilities, most often written by the parents themselves, talks about the stress and frustration this mistaken notion had on what is already a traumatic situation for the parents. Parents are often expected to make decisions for the good of the disabled child, without appropriate knowledge. Such expectations intensifies a crisis situation for mainstream Euro-Canadian mothers, and is even harder on non-English-speaking, culturally different mothers. Many of the issues highlighted above have yet to be thoroughly investigated.

This brings us to writers in the areas of disability and women. They too share similar concerns with the problems derived from homogeneous explications of women and people with disabilities within mainstream social sciences, claiming that there is a need to focus on difference or diversity as a means of more fully representing the complexities of the social world (Opie 1992:53). For example, Opie comments that from the feminist standpoint the role of informal female caregivers caring for family members at home is a prime example of the health system's (state) exploitation of family obligation (carer). Hence, feminists have placed great emphasis on the exploitation of the occupant of the caring role. Opie cautions, from her own analysis of her interviews with caregivers, such emphasis tends to represent the caring body as uniformly exploited (or uniformly willing). Her data showed that there have been odd moments of intimacy and tenderness between carer and care receiver, and during these intervals caring was not considered exploitative by the caregiver but rewarding (Opie, 1992:55). There is a disjunction between ideology (where caring is always defined as exploitative) and the experiential (where it is not) and this should be taken into consideration in any analysis on care.

CHAPTER V

GENERAL DISCUSSION AND CONCLUSIONS

In this study I have described the experiences of visible minority and immigrant women in their everyday lives and their interrelationships with the health care system. I have used current literature from North America, Britain, and other regions to illustrate my point that racial minority immigrant mothers of developmentally challenged young children have some commonalities - as a result of their immigrant and minority sociocultural roles and identities, the consequences of the migration process - with other immigrant women. As women living between two cultures (see Meleis, 1991), the dilemmas faced by immigrant women have been shown to be manifold. It has also been demonstrated in Chapter II that underneath the common immigrant facets are discrete differences between the women. Within the same racial or ethnic group, women's perception of their immigrant situations and how they define their needs may differ somewhat from each other on account of distinct personal and social characteristics. Li (1988) states that:

> a given ethnic group in North America is not likely to have come from a homogeneous source, and that an ethnic origin is likely to encompass people of different social backgrounds and different experiences.
>
> One may argue that, despite class and regional diversities, people of the same ethnic origin may still share a language, religion, and other cultural expressions sufficient enough to foster an ethnic identity or homogeneity. However, those who are familiar with ethnic communities are often struck by the prevalence of intra-ethnic conflicts and the absence of communal consensus . . . To argue that people of the same ethnic origin necessarily share the same culture, and therefore an identity, is to ignore the political and social complexities that exist within ethnic communities (p. 29).

Moreover, women who belong to the same race or ethnic group may face different demands and have different needs from women of other race or ethnic groups because of the unique properties of each group's cultural heritage and particular historical relationships with the ruling community.

> Each ethnic group has a unique history with respect to oppression and discrimination, and each has different emphases and values attached to academic pursuits, to family, to the respective roles of men and women, to the way the elderly are to be cared for, and to the ways in which religious teachings are translated into dictums for daily living. Social class factors join with factors arising out of ethnic history to give shape to how people will respond to the psychosocial problems they encounter in the course of living (Devore and Schlesinger, 1991: 49).

Chapter II highlighted some of the racial and sexist issues faced by immigrant minority women in their daily lives. It explored the thinking of feminist scholars (mostly Canadian), especially through a socialist feminist framework, to explain how the labels immigrant, women, and ethnic racial minority have been politically and economically constructed out of the women's relationships with the dominant community. A related dimension is the relationships between men and women in the home and in the labour market where gender inequity are most prevalent. From these two perspectives, I was able to look at the relationships between immigrant minority women and the health care system. In all three areas, the myriad of ideological and structural contradictions, hardships, and barriers made women's adjustment to a new culture a difficult task. Yet, they themsleves have been regarded by the dominant population as the source of their own problems.

Chapter III focused on the status of Canadian immigrants in relation to health care service delivery systems. Underutilization of health resources, in particular of mental health agencies, has been well-documented as a major factor with ethnic and racial minority immigrants in general and immigrant women in particular, especially those from the major Third World countries. The use of health services by minority populations has been limited by cultural and institutional barriers, for example: language problems; accessibility problems such as the inconvenient geographical location of agencies, lack of personal transportation, inadequate child care resources, hours of operation for working people, lack of bilingual staff, and/or available interpreter service; opposing the western medical model and home culture medical model; omission of the specific needs of a distinct minority group's health care needs in the development of programs and administration policies; and cultural insensitivity of health care agencies to the values, beliefs, and cultural practices of diverse ethnic groups.

In Chapter IV I have argued that ethnic minority immigrant mothers with children who have disabilities are the most frequent, and even continuous (if the child has moderate or severe impairment(s)), users of various health care agencies as well as social and special educational programs and institutions. I also argue that the difficulties experienced by ethnic minorites with the host culture's health care delivery systems are also faced by these mothers. However, the presence of childhood disability in the immigrant family means these mothers will more than likely encounter additional or different kinds of difficulties with health care agencies and professionals.

Moreover, as parents of children with disabilities, these women will have a different perception of motherhood than immigrant mothers whose children are not disabled. Such mothers may identify with Canadian mothers with disabled children in terms of their feelings and reactions (e.g., shock, sorrow, anger, denial, guilt and other reactions) to the child's disability, the everyday challenges of meeting the child's needs, and having to deal with society's prejudices toward disability. Nevertheless, cross-cultural and other empirical studies have found that parents' reactions and their utilization patterns of professional services and formal and informal support networks vary among mothers and between mothers from different cultural groups. Factors such as the women's ethnic and educational background, occupational level, cultural systems, belief systems, family composition and relationships, and social support environments (e.g., relatives, friends, neighbours, ethnic communitity, parent groups) have different effects on the reactions, adjustment process, and resource utilization patterns of mothers (and other family members) of handicapped individuals. In addition, factors such as a child's type of disability, degree of severity, age, sex, personality (how the child responds to the caregiver) are also important in terms of the mothers' reaction to the disability and child and service utilization behaviour. Institutional barriers such as the location of services, their hours of operation, the lack of on-site bilingual-bicultural professional staff, a generally insufficient system of delivering relevant information to ethnic minority families and communities are some problematic areas identified by ethnic minority parents of handicapped children.

One of the most noteworthy similarities between ethnic and racial minority and immigrant women in general and those women who have disabled children in particular is that both groups reported similar problems with existing health service delivery systems - such as lack of information of available services, cultural insensitivity, inaccessibility, and discriminatory treatment at all levels of health care delivery. In addition, traditional cultural values regarding mental health and disability and the historical racist and discrimnatory practices of dominant society towards certain ethnic and racial groups influence health seeking behaviour as well as service delivery. As a result, many disabled ethnic minoritities and ethnic minority persons with mental health problems are underrepresented in both mental health and developmental disabled service agencies.

As several studies have shown, limited knowledge about existing services and their features is a prominent problem with the mothers who have disabled children. However, Chan (1979) notes in his study of Asian families of developmentally disabled children that when informed of available specialized services (such as the Childrens Hospital of Los Angeles Regional Center), and their children's eligibility for them, many of the Asian families sought out these services immediately. Interestingly, most of the parents were more traditional and lack English language proficiency. The author suggests that this quick contact with CHLARC - as compared to non-Asian families and less traditionally (American born) oriented families - is due to the recent increase in the number of Asian families with disabled children entering the United States and the increase in referrals by ethnic service agencies.

Although ethnic and racial minority immigrant women differ from each other in terms of physical appearance, racial origin, cultural background, class, language, religion, education, and other attributes, their experiences are in many respect remarkably similar (see Anderson, 1987). For instance, they are affected (to a degree) by opposing home and host culture values; significant lifestyle and family structure changes, racial and gender inequalities in the work force and at home, and normal life transitions (e.g., birth, illness, death, and marriage). The women's new lives may be affected by additional problems such as the double burden of paid work and housework, feelings of isolation and loneliness, lack of fluency in the host language, and the absence of social support networks.

Birth origin and socioeconomic status are factors underlying some of these problems. For example, women born in Asian and South European countries generally do not have a knowledge of the host country's language and many are of working class background (Boyd, 1990). Without sufficient knowledge of the host country's language their social life is restricted to the home and ethnocultural community, and many never learned or felt the need to learn the new language. In addition, women who enter the labour force will find themselves relegated to the poorly paid segment of the labour force.

Beyond the dimension of individual social background, the lives of immigrant women are also shaped by the dominant ideologies of the new country. Unfortunately for many, such ideologies contradict those of the home culture. For example, some feminists and scholars writing about immigrant women indicate that the old culture's form of patriarchy differs from that of the new culture. In other words, western ideology of women's role situates women in the home and the western concept of family (nuclear) mean that immigrant women have to perform child care and housework alone. Not only are women expected to perform work (with no pay) in the home, they are also expected to work for wages outside the home. Immigrant men, on the other hand, are seen as the family providers whether they are employed or not. Women's role, in relation to men's role, is culturally deemed one of culturally less value (see Ortner, 1974; Rosaldo, 1974; see also Anderson, 1987; Begum, 1992; Dossa, 1990; Dua, 1992). Consequently, women's activities are seen as inferior to those of men. Male domination, oppression, and exploitation of women has thus been culturally legitimated, and the valuing of men over women can been detected in the ideological structures of virtually all societies (Rosaldo, 1974). Moreover, they are perpetuated in everyday practices. For example, the double work day (housework and paid work) of non-English speaking immigrant women is set in a way which does not allow them time for self-improvement or language training (Anderson, 1987:428). Even with help with housework, many women still find it difficult to leave the house since this is the place of their primary responsibility. However, one should consider the socioeconomic status of these women. Those in the middle- and upper-classes with or without English are subjected to experiences different from working class women. Another point to consider is that immigration and its difficulties may also affect the relationship between men and women.

However, although non-western cultures situates men and women in separate arenas (public and private, respectively) with culturally defined gender responsibilities. Women from these cultures are able to negotiate their women's role with the support and assistance of female family members or neighbours. Women of all class levels normally are not expected to do paid work outside the home. This is one big difference immigrant women from non-western countries commonly remarked on, especially those from traditional societies or rural areas. Changes in cultural ideologies (e.g., family structure and relationships, women's role and responsibility) between home culture and host culture affect the experiences of immigrant women. See below for further discussion on the changing inequality of gender relations and new society's expectations of immigrant women.

This then raises the question: How is it that when the women, who come from diverse personal, cultural, and social backgrounds, describe their resettlement experiences in Canada (and other regions) they sound so similar? To answer this, I looked at the common characteristics that bind them together: being an immigrant and being in a visible minority. Immigrant and visible minority are two terms which have been interpreted by members of the dominant community as interchangeable, the same. According to a new wave of scholarship these are terms defined and contructed in the historical and ongoing relationships between immigrant women and members of the host culture, and not individual attributes. In other words, they are ascriptive positions rather than birth rights. The women were not born immigrants or visible minorities, but were ascribed them when they emigrated to their new country. However, these women were born Chinese, Greek, Arab, Japanese, Korean, Mexican, and so on; and they have been raised by their parents to be Chinese, Greek, or Arab. Because each society focuses solely on the culture of normality (Gupta, 1990), women were socialized to be mothers of normal children not abnormal children. Therefore, when confronted with their own children who are born with birth defects or become disabled in an accident, mothers (if they are not afflicted with a disability themselves or have had previous experience with disabled people in the family) generally lack the cultural prescription for socializing this group of children (Mardiros, 1989). According to Murphy, Scheer, Murphy, and Mack (1988):

> Most disabled individuals, then, differ from members of other stigmatized groups in that they were not reared by disabled parents, nor did they grow up among disabled people. On the other hand, Jewish children, for example, are brought up by Jewish parents, often in neighborhoods with large concentrations of Jewish people; they are socialized to be Jewish and so learn how to deal with a sometimes hostile world. Disabled people receive no such socialization, not even the congenitally impaired, for they are usually brought up by parents who have no knowledge of the social problems of the disabled (p. 241).

Similarly, deaf parents of deaf children feel the same way about hearing teachers teaching deaf children because the former are socialized in a hearing world and the latter in a deaf culture (Erting, 1985).

A third characteristic the women share is being female. Although it is an acknowledged biological fact, it does not explain why women in general and immigrant women in particular are constantly struggling with the dialectical tensions between the ideologies embedded in the Canadian social institutions, and the regular practices of every day (Anderson, 1987:430). Biology does not fully explain why Canadian women find themselves confined to the domestic sphere. Immigrant women as females are expected to subscribe to the dominant society's notion of women's roles and related activities within the private sphere. In this they are similar to other Canadian women in many respects.

Some writers, however, have argued that to focus simply on gender relations is inadequate as an explanatory model of the situation and experiences of immigrant women. One also needs to examine race, class, ethnicity, and other social, economic, and political factors produced within the wider sociocultural context. The critics therefore proposed the development of a wholistic theoretical and methodological framework that not only emphasizes the everyday world of women's lives but also extends their practical existence to the larger social and cultural organizations and structures (e.g., economic, political, social, cultural, educational). It has been argued that the dominant ideologies which underpin these sociocultural institutions have tremendous influence on the things women do and how they perceive themselves and their immediate everyday world. In turn, when women define themselves according to the ideologies and carry out the tasks expected of them as immigrants, as women, and as minorities, they are endorsing and reinforcing the dominant ideologies embedded in the macro social and cultural structures.

Begum (1992) argues that both feminist and disability movements have largely overlooked the concerns and reality of being a disabled woman and having a physical disability. The feminist movement's tendency to focus on the issues of nondisabled women and the disability movement's tendency to ignore gender distinctions have effectively prevented disabled women from articulating their particular needs. Above all, the position of disabled women who are also coloured is made even more ambiguous and marginal by the fact that both movements treat every member as racially homogeneous or assume all women or disabled people have the same concerns, needs and experiences of oppression in a society that is sexist and handicapist. But, Begum points out, Black disabled women experience racism on top of sexism and handicapism (triple oppression).

Disabled women generally occupy what may be termed a no woman's land. Here, society expects them to live a life of passive dependency and restricted gender roles. For example, disabled women are regarded by society as devoid of sexuality (neutered). As asexual people they are believed to be incapable of fulfilling their traditionally defined role of wife and housekeeper (Begum, 1992:74-75; see also Dossa, 1990; Murphy et al., 1988). Subsequently they are relegated to the bottom of the social ladder undefined, marginalized, and even more devalued than women in general.

In the view of Murphy et al. (1988) disabled people are in a state of 'liminality', living in 'twilight zones of social indefinition' (p. 237). Influenced by the previous anthropological study of ritual (e.g., Durkheim, Mauss, Hubert, and van Gennep), the authors developed the liminality model which they argue is a more useful approach in the analysis of the social position of physically disabled people than Goffman's deviance model. Murphy et al. describe their model thus:

> Within this framework, the physically impaired are considered to be in a 'liminal' state, caught and fixated in a passage through life that has left them socially ambivalent and ill-defined, condemned to a kind of seclusion no less real than that of the initiate in the puberty rites of many primitive societies (p. 235).

For example, a person with disability is symbolically conceptualized as in a kind of limbo, where he or she is

> neither sick or well, neither fully alive nor quite dead. The sick role specifically tolerates and condones the suspension of the patient's ordinary rights and obligations on the assumption that it is temporary and that he [or she] will get better, as he usually does. He [or she] is then welcomed back into his [or her] full repertoire of roles and resumes his [or her] interrupted existence (p. 238).

In contrast, the conditions of physically or mentally disabled persons are not temporary but permanent, and recovery is not a matter of time as during an illness. Moreover, the sick role cannot be applied to some disabled people who do not require medication or constant care, though they cannot be called well if they are unable to move about freely without mechanical aid. Like the initiates of puberty rites, disabled people are the most liminal (suspension) during the transitional phase (the middle of the three stages in the rites of passage: separation, merger or transition, and reincorporation). However, unlike the initiates, reincorporation, the final stage, is never reached by handicapped people. At the third and final stage of the ritual, an initiate receives a new persona and is then reincorporated into his or her society under the new identity. However, during the liminal stage, initiates are considered at a threshold. Situated on the outside boundaries of society, initiates are allowed to re-enter society once they receive their new identity. On the other hand, disabled people live forever on the threshold of society, in a kind of limbo, undefined, and hence unwelcomed. Liminal people are perceived as 'unclean' or 'polluted' (see Douglas, 1955) and invisible. Such attitudes have been commonly felt by the paraplegic and quadraplegics in Murphy et al. ethnographic study.

Begum (1992) asserts that both feminist and disability movements need to acknowledge and learn from the experiences and contributions of disabled women in general (p. 53; see also Dossa, 1990) and Black disabled women in particular and to develop a movement which reflects the diversity of the sisterhood. An increasing number of empirical studies on this and other health issues in ethnic families have also emphasized the different needs within and between ethnic groups (see Chan, 1986; Devore and Schlesinger, 1991; Hessler et al., 1976). Szekely's (1990) advice is that when ethnic minority immigrant mothers are the focal point

> we must consider their experiences in the light of at least two sets of extended social relations - not only the current social relations in Canada but also those in the women's countries of origin. The experiences of immigrant women are historical, dynamic, and ever changing, as are the social relations from which their daily lives are inseparable (p. 126).

Bannerji (cited in Mukherjee,1990) believes that visible minority women can follow the example of some literature in the women's movement and stop talking about white people entirely, just as the women stopped talking about men (p. 149). Within the writings of feminists, only women's culture, needs, and so on are talked about. According to Bannerji, this is what literature about visible minority and immigrant women ought to be like:

> Yes, patriarchy is a point of reference for them [white women]. Racism is a point of reference for us [visible minority women]. I am not denying the fact that our lives are encrusted and surrounded by racism. But I still think that it is possible for us to stop talking about white people entirely. The dominant narrative is my life or your life or your child's life, and I will talk about white people only as they enter this dominant narrative . . . There are areas of our lives, areas where we shop and read and live and love poetry or clothes, where we live like every human being lives, in the world, in some sensuality - and not just sexuality - and the white people will not enter that part of my narrative (p. 149).

However, there is a tendency for social science and feminist writers to portray ethnic and racial minority, or immigrant women, and especially women with disabilities (see Begum, 1992; Dossa, 1990), as helpless victims of the larger society or uniformly exploited by the health care system (Opie, 1992). In addition, overstressing the lack of training, skills, education, and resources of immigrant women in general conceals the fact that there are notable differences within this group of women. Contrary to the general assumptions about female immigrants, particularly the ones from Third World countries, being unskilled, uneducated, and at the lowest socioeconomic echelon of their particular society, a good number of the women are highly educated, skilled, and may have enjoyed high socioeconomic status in their country of origin.

Dossa (1990) objects to feminists' treatment of women with disabilities as victims of society because it only stereotypes them as dependents of society's social services. The assumed notion that they need to be helped and assisted to become autonomous and distinct individuals is, according to the author (p. 37), one that exists only in western society; whereby a person is thought of as a self-determined as opposed to a socially-determined being. Dossa prefers to see women with disabilities in a theoretical model that perceives them in sharing and reciprocal relationships with society rather than being its dependents (p. 37). This is how ethnic mothers caring for disabled children should be regarded as well by helping services professionals and in society. Although the ethnic minority mothers are overwhelmed by the prospect of raising a child with a disability or the stigma of having given birth to a handicapped child to self, child and family (Chan, 1979; Moyes, 1981; see also Buscaglia, 1983; Goffman, 1963; Pivato, 1991), their resourcefulness and capability to meet the demands of the child should not be undermined.

Many of these mothers' health and well-being may be affected both by the negative consequences of the immigration process and the physical, emotional, and psychological distress of having the primary responsibility of coping with and managing the demands of a special needs child and the constant interaction with special health care and other related professionals. Findings in the area of family roles revealed that women are predominantly responsible for child care in the household. This is the case regardless of whether the child is handicapped or not and the mother works outside the home or not. The growing trend for families with severely disabled children to care for them in the home, as a result of changes in societal attitudes toward home care as well as the lack of financial resources for residential treatment or institutionalization, means no more than that the burden of the care will be undertaken by the primary caregiver in the family, which is the mother (Weiss, 1991:203; see also Ayer and Alaszewski, 1986; Beckman-Bell, 1980; Mary, 1986; Miller-Bank, 1986; and other works cited). When government policies and society's changed attitude pushed and endorsed the concept of community care for people with mental and physical disabilities under the ideology of integration and the associated concept of normalization, they in fact transferred the bulk of community responsibility from the state to family carers, namely women. The exploitative relationship between the modern state health care system and informal caregivers has been a contentious issue with feminist writers (see Opie, 1992).

As was said in the introduction, this study is an attempt to draw attention to a virtually neglected area in disability, feminist, and immigrant research: the situation and experiences of Canadian immigrant mothers from various cultural groups who are raising handicapped children. There are few studies or reports concerning this aspect of immigrant women's lives. Meleis (1991) remarks that many feminist writers and researchers have noted the paucity of data related to women and their daily lives and advocate that filling this gap be made a priority with scholars (pp. 373-374).

Disability should also be a priority for future research on immigrant women's lives for three reasons. First, there is a great void in the immigrant knowledge base on this topic. Second, there is a rapid growth of minority populations in major North American centres. Third, disability is one of the many life events (e.g., marriage, birth, death, puberty) that is becoming a serious problem for present and future populations in Canada and other industrialized nations because of the dramatic technological, environmental, and social changes which have taken place. The miracle of science certainly increases the survival rates of extremely premature babies. With the development of intensive care within the last decades, only about fifteen to twenty percent of very low birth-weight and premature infants suffered any major handicaps; whereas, in the early 1970s, the percentage was around fifty to sixty. However, these babies have a higher incidence of serious complications later in life, such as cerebral palsy, mental retardation, blindness, jaundice, collapsed lungs, and infections (Winzer et al., 1987:27).

Birth complications do happen and it can be dangerous for the infant and mother. Problems at birth or during pregnancy occur without socioeconomic and colour discrimination. It can happen to a recent immigrant woman as well as to a woman who has been in North America for many years. Additionally, advanced technology in medicine means that people have a longer life span, but it also means that a higher number of the elderly might be living with disability due to an extended aging process. Given the increasing number of child bearing age and elderly immigrant and refugee women entering Canada and the United States in recent years, I hypothesize that the incidence of birth complications leading to child disability and aging complications leading to elderly disability will increase in the ethnic population. We need to consider seriously the question of disability in the lives of immigrant women since the task of caring for the disabled family member will fall on them. As Ayer and Alaszewski (1986) have pointed out, family care inevitably implies woman's care. Having a disabled member in the family is a stressful and overwhelming burden to immigrant mothers who may already be inundated with normal family demands and trying to adapt to a new environment. The impact of a disabled child on immigrant families, especially on the mothers, cannot be underestimated.

Some recent works have maintained that further research into health care issues should start with theoretical models that recognize the diversity in attitude, behavior, and belief among people and the variations between and within communities, cultures, and societies (Hessler et al., 1978:362). The concept of diversity is becoming a popular alternative to the uniformity/ homogeneity theory among western researchers in various aspects of health care study, and in other non-health related studies as well. From the standpoint of diversity, researchers argue for the incorporation of social and cultural factors (e.g., religion, age, race, ethnicity, education, gender, economic status, and others) into research designs and analysis.

Although Westermeyer (1979) states that similarities in the major concepts of mental disorder such as mental retardation and psychosis exist in many societies, he too is of the opinion that there is a diversity between and within the cultural groups that appears to be rooted in the cosmologies (p. 315).

Visible minority immigrant women should not be assumed to be homogeneous in regard to these issues. Each person's unique personal and social characteristics, and childhood socialization processes (see Danna, 1980) are factors that set women's concerns in their lives apart from each other and from the men. In other words, what one woman sees as a problem warranting help may not be seen in the same way by another. This is also true among women and men of the same cultural group. However, the lives of immigrant women are much influenced by the type of patriarchy present in the host society. Although they carry with them the patriarchical law of their homeland, the latter is often found to be in contradiction to the new one. Patriarchy defines the parameters of the social and economic positions and roles of men and women in a way that creates an asymmetry of power and value between men and women. Women occupied the less valued domain of the home and role of nurturer and reproducer. Child care and housework are two of the unrewarded responsibilities performed by women, in ideological and labour market value. At the same time, western capitalist notions of individual independence and autonomy mean that women fulfill their role and responsibilities alone, as a separate entity (to borrow from Dossa, 1990). In most non-western societies, individuals are regarded as social beings who are an integrated part, rather than an independent aspect, of one's community.

Many ethnic and racial minority immigrants' attitudes toward health and illness have been formed in their country-of-origin. Furthermore, this knowledge is sustained within ethnic communities where members can share traditional cultural health and illness beliefs, myths, attitudes, and superstitions. If psychological disorders such as mental illness and major visible congenital defects such as cleft palate or Down's syndrome are traditionally stigmatized in the home country, then these negative conceptions are found within ethnic minority communities in their new country. However, ethnic groups or communities are dynamic, changing and modifying over time as they interact with the larger society. They adopt certain dominant ideologies and behaviours, but retain their ethnic identities and cultural heritage (see Lipson and Meleis, 1990).

Trying to understand the everyday lives of ethnic and racial minority immigrant mothers caring for a disabled child is not an easy task; there are too many anomalies that come into play which make each mother's life circumstances unique and at the same time similar to other mothers intraculturally and interculturally. Therefore, it is of vital importance that researchers and professional services providers and policy makers look beyond the immediate social or health problem and the person as she appears at the moment to social, cultural, familial, and other factors surrounding her life.

5.1 Research Strategies with Immigrants, Immigrant Women, and Racial Minority Parents of Disabled Children

Research on ethnic and racial minority immigrant groups in general and immigrant women in particular, whether they have a disabled child or not, is frequently plagued by underpresentation of these populations in the research samples and overrepresentation of whites (see Thompson, 1984). The hardest task is to obtain the consent of minority individuals to participate in the study. Thompson writes that achieving racial composition of the sample which is consistent with the larger population composition is an ever-present concern to researchers. In an attempt to address this problem, Thompson examined the parental consent rate of Black parents with children at a shcool for the physically disabled. She found that personal communication with the parents about the study via a phone call was the most effective, albeit the most time consuming. She used three other methods, namely an incentive to the child to participate, an incentive to the parent to participate, and communication with the child about the study.

Lipson and Meleis's (1989) article on the various methodological difficulties encountered by researchers in health research with immigrants is a useful guide to the design and implementation of an appropriate and culturally sensitive study and health program focusing on visible minority and immigrant mothers of developmentally disabled children. It shows the pitfalls and successes of previous researchers with particular methodologies and strategies. The discussion was interspersed with examples from a continuous study on the immigration experience, ethnicity and health status, beliefs and behavior of Middle Eastern immigrants in the United States.

Although previous findings on Middle Eastern immigrants were used to illustrate various aspects of the discussion, the authors point out that the research problems noted with Middle Easterners could easily be found in other immigrant groups. One of the major problems encountered in research on health issues among immigrant populations is obtaining a representative sample of the population and being able to identify the universe of the immigrant groups (both are *de rigeur* with research) (p. 104). Sampling difficulty is caused by frequent conflicting reports from various sources (such as the United States Census and embassy and immigration statistics) on the actual number or the characteristics of an immigrant group. Another problem is that immigrants are not concentrated in the ethnic communities but scattered all over the United States.

Another problem in obtaining adequate population representation may be the recruiting of informants for the study. The authors consider that picking names out of a phone book or mailing requests would be ineffective means of obtaining participants, especially with immigrant groups which put great value on personal contact. The 'snowball' method may be a good *modus operandi* but does not represent the whole population, only those who agreed to participate. Another way of obtaining informants for a study of immigrant health is through the various health care services in which immigrants are clients. However, even this Lipson and Meleis found problematic because it tends to highlight pathology, which in turn makes a particular health problem (e.g., mental illness) seem more prevalent or serious among immigrant groups than is really the case. Similar concerns have been expressed by Chan (1979) regarding the use of the Childrens Hospital of Los Angeles Regional Center to solicit participants for his study on the service needs of developmentally disabled Asian children and their families. His end results, however, revealed that although Asian clients (the disabled children) differ from non-Asian clients in their distribution of levels of retardation, the former were not more severely retarded than the latter. Chan's finding contradicts previous studies which found that Asian clients were more severely retarded than non-Asian clients, including Lipson and Meleis's research on immigrants and their health.

Another major problem found by Lipson and Meleis is that immigrants, especially recent immigrants, generally distrust researchers because of their assumed association with government and public agencies (see also Chan, 1979). Their precarious status as non-citizens makes them suspicious of any research requiring information from them. They also fear that relatives who do not have legal visas may be found out during the interviews. Those who experienced war or political upheaval in their home country tend to distrust strangers.

Also, recent immigrants often do not understand the intent of health research with immigrants even though they are willing to participate and recognize the benefits to themselves and their families. The notion that their knowledge may benefit society at large is a difficult concept to grasp. "In some cases, such distrust is engendered by research studies that negatively stereotyped immigrants or represented them as being marginal people who have higher rates of maladjustment or mental illness than the general population" (Lipson & Meleis, 1989:104-105). Distrust of researchers may also be expressed by the presence of non-participating family members throughout the interviews.

Interview style can 'make or break' a research study. If the content or questions are inappropriate or culturally insensitive, an informant may refuse to answer, or terminate the interview. In addition, some participants give answers which they think will please the researcher. To 'save face' is important in many immigrant groups. Thus, immigrants tend to keep any problems such as health, familial, marital, or personal within the family or to themselves. Individuals may present their public self or private self depending on the situation.

Researchers should also be aware that immigrants who consent to participate in the study may expect a favour in return from the researchers. It may be a letter of recommendation or advice. Previous researchers conceptualized this in terms of reciprocity, in which the informant expects something for their trouble. However, Lipson and Meleis note that such favours indicate that the researcher is trusted by the Middle Eastern immigrants. Moreover, non-termination of the interview is also a sign of trust. In other words, the relationship between researcher and informant normally ceases at the end of the research; however some immigrants perceive this as the beginning of a friendship. According to the authors, developing trust is important for the success of an interview. A good way to develop trust is to ensure that the interview text and interviewer are culturally sensitive. Interviewers should also be aware of the different symbols of trust within various immigrant groups. The sharing of food is a fairly universal sign of trust. Refusal of food offered is considered an insult. The ethnicity of the researcher is also important in terms of the amount and accuracy of the data provided by participants. Immigrant participants feel that there are concepts and words that are not translatable, but which an interviewer who is of the same ethnic background would understand. In addition, asking some immigrant participants to sign a consent form may not be an easy task. For these people, verbal consent is enough to show their commitment to the researcher, and a written consent implies a lack of trust. This is a dilemma for researchers who must comply with academic institutional policies on research ethics.

In a more recent article, Meleis (1991) asserts that "an understanding of the health-care needs of bicultural women, through whatever research design is chosen, has to be mediated through being from that culture, collaborating with others who are from that culture, and immersing oneself in that culture" (p. 373). In other words, Meleis firmly believes that the best way to know about a population is to be an integral part of that population (see Ragucci, 1978). This was Ragucci's approach more than a decade ago. While she was studying the health beliefs and practices of women in an Italian American community, Ragucci rented an apartment within the community and lived among the women throughout the fifteen months of her data collection. Her acceptance was determined by her status (graduate student), purpose (studying traditional health practices), and the type of apartment she had rented (i.e., a cold water flat would have lowered her standing and a remodeled luxury apartment would have increased social distance). These kinds of cultural nuances, especially for a researcher who is not of the ethnic group being studied, could only be recognized and understood only when the investigator is living in the ethnic community and in the culture.

Research strategies with ethnic minority immigrant parents who have a disabled child should be culturally relevant and sensitive to the feelings of the parents. Disability is a sensitive topic, and for many parents who come from Third World and South European countries, a shameful one. It is most likely because of cultural stigma, as well as the tremendous heartache an interview will provoke, that parents are unwilling to talk with researchers. Once researchers have gained the consent of ethnic minority parents' to be interviewed, the most important step is to ensure that their research designs are sensitive to the individual's particular culture and personal background (e.g., educational level, economic status, religious beliefs, length of residence in the host country, spoken language preference). In addition, family socialization processes such as culturally-related familial role expectation, parent-child interaction patterns, and child-rearing values and practices should be considered by researchers (Chan, 1979:121). Chan also recommends that research undertakings should be at an interpersonal level; that is, personal interaction with the participants. This is very important in Asian cultures. Another useful research strategy implemented by Chan was the use of bilingual staff from the Regional Center to act as translators during the interviews and to translate the taped materials. Because the bilingual staff are specialists in the area of developmental disabilities and of the same ethnic background as the participants, the latter were more willing to talk about their needs and concerns.

5.2 Concluding Remarks

Almost a decade and a half has elapsed since Chan (1979) identified the areas in which there are gaps in our knowledge of Asian American disabled people and their families in the health service delivery systems, and yet very little has been done since then on this particular or other ethnic minority population who are living with disabilities. Secondly, even though there is increasing interest in the health problems afflicting immigrant ethnic minority women in both health and social sciences disciplines, physical and mental disabilities are seldom considered. All research on health issues relating to immigrant and/visible minority groups needs to take into account that disability is a fact of life for a majority of these people at certain points of time in their life as well as the non-immigrant and/non-visible minority groups. The literature examined and personal observation have indicated that through accident or nature we ourselves or a member of the family may be disabled. We all suffer with the knowing.

Unfortunately, for some of us, there are other factors which make it even more difficult to come to grips with being disabled or the responsibility of caring for a family member with a disability. I am, of course, referring specifically to immigrant and/ethnic minority mothers of handicapped children. The stresses white, Canadian mothers experience with their handicapped children as the previous chapters have argued most likely double, if not triple, for immigrant women. This is especially the case for those who cannot speak English well enough to communicate with professionals and paraprofessionals working with their disabled children, who are unfamiliar with the health care systems or services of the new society, who are facing the hostile attitudes of their ethnic communities and society at large, who have the burden of caring for the disabled child and family as well as working outside the home, who have to battle with social and health institutional barriers, and who do not have access to either formal or informal support networks. These are the problems identified in the few available research studies on ethnic minority parents of children with disabilities. Besides these problems, immigrant women must also deal with the negative aspects of immigration and being an immigrant and a minority. The literature on immigrant women in general and the works on the health concerns of immigrant women in particular provided this author with insights into the experience and situation of immigrant ethnic minority women as immigrants and as an ethnic minority. It also support my argument that these mothers are at an even higher risk for mental and physical problems than immigrant women in general. Moreover, there are also recent findings reporting on the abuse of women and handicapped children. This is another facet of the lives of immigrant women in general which is gaining public attention, particularly through non-profit women and/ immigrant and/ethnic organizations and agencies.

Research, especially ethnographically and qualitatively designed, is much needed in order for existing health and social service delivery systems to be culturally appropriate and effective in meeting the needs of both immigrant ethnic minority mothers and their handicapped children. In addition, as pointed out by Chan (1979:120), there should be parallel quantitative research efforts that specificially identify and document the prevalence and distribution of developmental disabilities among various ethnic minority populations. At present, census and other demographic data do not separate these people from other categories or else they are subsumed under various general disabled populations. As informal caregivers of these children, the mothers have a lot to do with their well-being and development. In essence, research should be formulated in such a way that will allow immigrant mothers raising a child with disability to speak about their experiences from their own perspective. This kind of personal narrative is personal because it takes into account the women's particular personal history as well as their general social and cultural history. This review of available literature has pointed to a gap in our knowledge of immigrant and ethnic minority mothers caring for children with disabilities in Canada and other industrialized western nations such as Britain and the United States. Mary (1986) offers some sound advice to professionals:

> [they] need to consider a more wholistic approach to working with families of disabled children. That is to say, no matter what service [they] deliver, the parents' needs are equally important and they are not unidimensional. No matter what the socioeconomic level or ethnic background all parents struggle to develop new skills and knowledge with which to better nurture their child and are wrestling, at the same time, with mixed emotions toward these [a?]typical infants. Meaningful service may mean addressing both of these struggles (p. 179).

I agree with Mary that all too often professionals are so focused on the needs of the children with disabilities that they do not give much thought to the parents. The development and well-being of the children are as much the work of parents as professionals, if not more so. Parents care for their children twenty-four hours a day, whereas professionals see them for a short time during appointments.

The literature about children with disabilities and on parents of disabled children showed the interest of professionals in these subjects. However, this merely emphasized the dearth of information on the subject of ethnic and racial minority children with disabilities and parents of disabled children. Even within the available literature on this particular topic there has been a focus on particular ethnic and racial minority groups. Blacks, Hispanics, and Asians are the three groups which appear most often in cross-cultural or unicultural studies. Among the multiethnic advanced capitalist western countries, it is the United States which has been studied in regard to visible minority and/or immigrant families with disabled children. At present, there are a few studies on South Asians in regard to disability. Gupta (1990) in Britain and Begum (1992) in Canada are the two I have come across to date. In comparison, there seems to be more books and papers on and by South Asian North American and British women covering different dimensions of their lives (e.g., Dua, 1992; Ralston, 1988, Mukherjee, 1990) and health (Anderson, 1987), but little attention has been paid to disability (with the exception of Gupta's and Begum's works). This literature, on the whole, focused on the influence of gender, class, and racial (and handicapping) factors on the subjective experiences of South Asian women.

Noticeably absent in this literature is the dimension of religion and the role it plays in shaping the women's everyday life in the home and the wider community. Common sense indicates that the majority of South Asian women are strongly affiliated with one of the various Asian religions - Hinduism, Sikhism, and others. Similarly, the religious pattern of Hispanics, Blacks and Asians is identified in some of the literature. Specific folk belief systems (e.g., ancestor worship, magic and sorcery, divine intervention) have figured in a few studies (see Chan, 1979; Mardiros). They have been found to have an effect on the perception by and reaction of parents to their disabled children and on parents service utilization behaviour. The folk religious system has been examined with regard to Asian and Hispanic families with disabled children. Although some Asians claimed to be members of various Christian church organizations (e.g., Roman Catholic, United Church, Presbyterian), the authors tend to ignore this. Recent Canadian census data showed changes in the religious pattern of Asian groups. The largest number of Asians reported no religion and the next largest number indicated membership in one of the various Christian denominations. In the last fifty decades, the number of Asians who are members of an Asian religion has drastically decreased. Future researchers need to pay closer attention to the religious patterns of immigrant and minority groups because more and more seem to have adopted the Christian faith. Again, this shows that even in religious beliefs, Asian groups differed from each other and within their own ethnic community. In addition, the possibility of religious organizations as sources of support for immigrant mothers of disabled children should be investigated. With ethnic and racial minority communities which are closely tied to their religion, to the extent that the people's personal lives revolved around it, what kind of comfort can the mothers get from their religion? A related question is: what kind of (or lack of) assistance can mothers obtain from their congregation?

Studies of the health issues and/or immigrant experiences of ethnic and racial minority women have been primarily among Asian, South Asian, African, Southeast Asian, Central American, South European, and Middle Eastern groups in North America. Under these broad ethnic labels (derived from general geographical regions) is the specific ethnicity of the women who have been studied: Asian: Chinese, Japanese, Korean. Southeast Asian: Thai, Filipino, Vietnamese, Malaysian. South Asian: Sri Lankan, Indian, Pakistani, Bangladeshi. Central American: Mexican. South European: Greek, Italian, Sicilian. Middle European: Arab, Palestinian, Armenian, Persian who come from Egypt, Jordan, Israel, Lebanon and Iran. One of the problems I found with such inclusive ethnic labels is the lack of agreement between researchers regarding which specific ethnic groups should be included under each ethnic-geographical category. In Chan's study, Asians also referred to those who others identified as Southeast Asians. People who migrated from South Asia, East and South Africa, and the Caribbean are also labeled South Asians (Ralston, 1988:64). The drawback of such a broad ethnic-geographic term is that it presents an image of a homogeneous group, when it is obvious that the specific groups included people of different political and historical backgrounds. For example, Chinese women born in mainland China have a personal background that may have been influenced by Communism and a traditional culture; whereas those born in Hong Kong carry with them one that is shaped by capitalism and western attitudes. Despite the same ethnic ancestry, these women will perceive their immigration experiences and their disabled child differently.

Because little research has been conducted on immigrant minority women with disabled children, there is plenty to be done. The kind of research which is most informative would be that which investigates the manner in which the powerful factors of gender, religion, class, ethnicity, patriarchy shaped the experiences of women with disabled children. Another area to examine is the female support networks as a female institution appropriated by women as a means to oppose and protect themselves against patriarchy. A third area for study is how the terms disability, immigrant, minority, and women are constructed by the women. In other words, through their experiences in the new culture, what meanings have they attached to these terms? This is something which is missing in the literature. Finally, the length of residence in the host country has been noted but it did not seem to have much bearing on the analysis of the material examined. The degree of acculturation would have some kind of influence on the attitude of parents toward the disabled children and their help-seeking behaviour. A comparison between recent racial minority immigrants parents and those who have been in the country for many years is yet another gap in the present literature. Any study with this group of women will increase our knowledge, as professionals, scholars, and interested citizens, of their world. In addition, it will allow these women to speak of their experiences and express their realities; to emerge from their invisibility (a contradiction to their physical appearance and political position) to be present in both voice and appearance.

BIBLIOGRAPHY

Anderson, J.M. (1987). Migration and Health: Perspectives on Immigrant Women. *Sociology of Health & Illness*, 9, 410-438.

Anson, O. (1988). Living Arrangements and Women's Health. *Social Science and Medicine*, 26, 201-208.

Awaritefe, A. (1989). Epilepsy: The Myth of a Contagious Disease. *Culture, Medicine and Psychiatry*, 13, 449-456.

Ayer, S., & Alaszewski, A. (1986). *Community Care and the Mentally Handicapped: Services for Mothers and Their Mentally Handicapped Children.* London: Croom Helm, Ltd.

Barile, M. (1992). Disabled Women: An Exploited Underclass. *Canadian Woman Studies*, 12, 32-33.

Barrow, M.V. (1977). A Brief History of Teratology to the Early 20th Century. In T.V.N. Persaud (Ed.). *Problems of Birth Defects.* Baltimore: University Park Press.

Beckman-Bell, P.J. (1980). *Characteristics Of Handicapped Infants: A Study of the Relationship Between Child Characteristics and Stress as Reported by Mothers.* Unpublished doctoral dissertation, University of Carolina.

Begum, N. (1992). Disabled Women and the Feminist Agenda. *Feminist Review*, 40, 70-84.

Biller, H.B. (1993). *Fathers and Families: Paternal Factors in Child Development.* Westport, Connecticut: Auburn House.

Boyd, M. (1990). Immigrant Women: Language, Socioeconomic Inequalities and Policy Issues. In S.S. Halli, F. Trovato, & L. Driedger (Eds.). *Ethnic Demography: Canadian Immigrant, Racial and Cultural Variations.* Ottawa: Carleton University Press.

Bromley, B., & Blacher, J. (1989). Factors Delaying Out-of-Home Placement of Children With Severe Handicaps. *American Journal on Mental Retardation*, 94, 284-291.

Brown, R.I. (1991). Changing Concepts of Disability in Developed and Developing Communities. In D. Mitchell, & R. I. Brown (Eds.). *Early Intervention Studies for Young Children with Special Needs.* London: Chapman and Hall.

Buscaglia, L. (1983). *The Disabled & Their Parents* (revised edition). New York: Holt, Rinehart and Winston.

Chan, S.Q. (1979). *Services for the Developmentally Disabled: A Study of Asian Families Within a Regional Center System.* Unpublished Doctoral Dissertation, University of California, Los Angeles.

Chow, E.N.-L. (1989). The Feminist Movement: Where Are All the Asian American Women? In Asian Women United of California (Eds.). *Making Waves: An Anthology of Writings By and About Asian American Women.* Boston: Beacon Press.

Christensen, C.P. (1987). The Perceived Problems and Help-Seeking Preferences of Chinese Immigrants in Montreal. *Canadiann Journal of Counselling*, 21, 189-199.

Couch, R.H., Goetz, J.P., & Baud, H. (1991). Living with Disability in Guatemala. *Journal of Rehabilitation*, 57, 46-52.

Danna, J.J. (1980). Migration and Mental Illness: What Role Do Traditional Childhood Socialization Practices Play? *Culture, Medicine and Psychiatry*, 4, 25-42.

Devore, W., & Schlesinger, E.G. (1991). *Ethnic-Sensitive Social Work Practice*, (3rd ed.). Toronto: Collier Macmillan Canada, Inc.

Dossa, P.A. (1990). Women and Disability: The Myth of the Autonomous Individual. *Journal of Practical Approaches to Developmental Handicap*, 4, 37-42.

Douglas, M. (1955). *Purity and Danger: An Analysis of the Concepts of Pollution and Taboo.* .London: Routledge & Kegan Paul.

Dua, E. .(1992). Racism or Gender? Understanding Oppression of South-Asian Canadian Women. *Canadian Woman Studies*, 13, 6-10.

Eberly, S.S. (1988). Fairies and the Folklore of Disability: Changelings, Hybrids and the Solitary Fairy. *Folklore*, 99, 58-77.

Erickson, M., & Upshur, C.C. (1989). Caretaking Burden and Social Support: Comparison of Mothers of Infants With and Without Disabilities. *American Journal of Mental Retardation*, 94, 250-258.

Erting, C.J. (1985). Cultural Conflict in a School for Deaf Children. *Anthropology & Education Quarterly*, 16, 225-243.

Funk, R. (1987). Disability Rights: From Caste to Class in the Context of Civil Rights. In A. Gartner, & T.Joe (Eds.). *Images Of The Disabled, Disabling Images*. New York: Praeger Publishers.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, N.J.: Prentice-Hall, Inc.

Gowen, J.W., Johnson-Martin, N., Goldman, B.D., & Appelbaum, M. (1989). Feelings of Depression and Parenting Competence of Mothers of Handicapped and Nonhandicapped Infants: A Longitudinal Study. *American Journal on Mental Retardation*, 94, 259-271.

Gupta, R. (1990). Giving Birth Again.In K.Gieve (Ed.). *Balancing Acts: On Being A Mother*. London: Viago Press.

Haffter, C. (1968). The Changeling: History and Psychodynamics of Attitudes to Handicapped Children in European Folklore. *Journal of the History of Behavioral Sciences*, IV, 55-61.

Hahn, H. (1987). Civil Rights for Disabled Americans: The Foundation of a Political Agenda. In A. Gartner, & T.Joe (Eds.). *Images Of The Disabled, Disabling Images*. New York: Praeger Publishers.

Hallsted, B.D. (1988). Our Son Lives at Home. *Exceptional Parent*, 18, 18-23.

Hannam, C. (1988). *Parents and Mentally Handicapped Children* (3rd ed.). Bedminster: Bristol Classical Press.

Heath, R., & Levin, P. (1991). Cultural Sensitivity in the Design and Evaluation of Early Intervention Programmes. In D. Mitchell, & R.I. Brown (Eds.). *Early Intervention Studies for Young Children with Special Needs*. London: Chapman and Hall.

Herberg, E.N. (1989). *Ethnic Groups in Canada: Adaptations and Transitions*. Scarborough, Ontario: Nelson Canada.

Hessler, R.M., Nolan, M.F., Ogbru, B., & New, P.K.-M. (1978). Intra-ethnic Diversity: Health Care of the Chinese Americans. In M.H. Logan, & E.E. Hunt, Jr. (Eds.). *Health and the Human Condition: Perspectives on Medical Anthropology*. Belmont, California: Wadsworth Publishing Company.

Hutcheon, L., & Richmond, M. (1990). *Other Solitudes: Canadian Multicultural Fictions*. Toronto: Oxford University Press.

Kojima, Y. (1977). Disabled Individuals in Japanese Society. *Rehabilitation World*, 3, 18-25.

Lagerkvist, B. (1992). Community-based Rehabilitation - Outcome for the Disabled in the Philippines and Zimbabwe. *Disability and Rehabilitation*, 14, 44-50.

Li, P. (1988). *Ethnic Inequality in a Class Society*. Toronto: Wall & Thompson.

Lipson, J.G., & Meleis, A.I. (1989). Methodological Issues in Research with Immigrants. *Medical Anthropology*, 12, 103-115.

Maloof, P.S. (1981). Fieldwork and the Folk Health Sector in the Washington, D. C. Metropolitan Area. *Anthropological Quarterly*, 54, 68-75.

Mardiros, M. (1989). Conception of Childhood Disability Among Mexican-American Parents. *Medical Anthropology*, 12, 55-68.

Marfo, K. (1991). *Early Intervention In Transition: Current Perspectives on Programs for Handicapped Children*. New York: Praeger Publishers.

Mary, N.L. (1986). *A Cross-Cultural Study of Mothers Of Young Developmentally Disabled Children*. Unpublished Doctoral Dissertation, University of California, Los Angeles.

Mba, P.O. (1983). Trends in Education of Handicapped Children in Developing Countries with Particular Reference to Africa. *B. C. Journal of Special Education*, 7, 273-278.

McPherson, C. (1992). Tackling Violence Against Women with Disabilities. *Canadian Woman Studies*, 12, 63-65.

Meleis, A.I. (1991). Between Two Cultures: Identity, Roles, Health. *Health Care for Women International*, 12, 365-377.

Miller-Bank, C.L. (1986). *The Effect of Mother's Self-Esteem and of Social Environmental Support on the Acceptance of Her Handicapped Child.*. Dissertation, New York University.

Mitchell, D., & Brown, R.I. (Eds.). (1991). *Early Intervention Studies for Young Children with Special Needs*. London: Chapman and Hall.

Moraga, C., & Anzaldua, G. (Eds.). (1983). *This Bridge Called My Back: Writings by Radical Women of Color*. New York: Kitchen Table, Women of Color Press.

Moyer, A. (1981). *One In Ten: Disability And The Very Poor.* Oxford: Oxfam.

Mukherjee, A. (1990). Himani Bannerji (b.1942), The Other Family. Interview by A. Mukherjee. In L. Hutcheon, & M. Richmond (Eds.). *Other Solitudes: Canadian Multicultural Fictions*. Toronto: Oxford University Press.

Mullins, J.B. (1987). Authentic Voices From Parents of Exceptional Children. *Family Relations*, 36, 30-33.

Murphy, R.F., Scheer, J., Murphy, Y., & Mack, R. (1988). Physical Disability and Social Liminality: A Study in the Rituals of Adversity. *Society, Science, and Medicine*, 26, 235-242.

Murphy, Y., & Murphy, R. F. (1985). *Women of the Forest* (2nd ed.). New York: Columbia University Press.

Ng, R., & Ramirez, J. (1981). *Immigrant Housewives in Canada.* Toronto: The Immigrant Women's Centre.

Nyakabwa, K., & Harvey, C.D.H. (1990). Adaptation to Canada: The Case of Black Immigrant Women. In V. Dhruvarajan (Ed.). *Women and Well-Being/Les Femmes Et Le Mieux-Etre.* Montreal & Kingston: McGill-Queen's University Press.

Opie, A. (1992). Qualitative Research, Appropriation of the 'Other' And Empowerment. *Feminist Review*, 40, 52-69.

Ortner, S. (1974). Is Female to Male as Nature is to Culture? In M. Rosaldo, & L. Lamphere (Eds.). *Women Culture and Society: A Theoretical Overview.* Stanford, California: Stanford University Press.

O'Sullivan, M.J., Peterson, P.D., Cox, G.B., & Kirkeby, J. (1989). Ethnic Populations: Community Mental Health Services Ten Years Later. *American Journal of Community Psychology*, 17, 17-30.

Pakrasi, K., Basumallik, T., Chowdhury, S., & Chakraborty, M. (1987). Mentally Retarded Children of Eastern India: A Biosocial Study. *Social Biology*, 34, 206-219.

Pang, K.Y.C. (1990). *Hwabyung* : The Construction of a Korean Popular Illness Among Korean Elderly Immigrant Women in the United States. *Culture, Medicine and Psychiatry*, 14, 495-512.

Pelto, P.J., & Pelto, G.H. (1978). Medicine, Anthropology, Community: An Overview. In M.H. Logan, & E.E. Hunt, Jr. (Eds.). *Health and the Human Condition: Perspectives on Medical Anthropology.* Belmont, California: Wadsworth Publishing Company.

Pivato, E. (1990). *Different Hopes, Different Dreams.* Edmonton: Academic Printing and Publishing.

Ragucci, A.T. (1978). The Ethnograhic Approach and Nursing Research. In M.H. Logan, & E.E. Hunt, Jr., (Eds.). *Health and the Human Condition: Perspectives on Medical Anthropology.* Belmont, California: Wadsworth Publishing Company.

Ralston, H. (1988). Ethnicity, Class and Gender Among South Asian Women in Metro Halifax: An Exploratory Study. *Canadian Ethnic Studies*, XX, 63-83.

Reiter, S., Sami, M., & Rosenberg, Y. (1986). Parental Attitudes Toward the Developmentally Disabled Among Arab Communities in Isreal [sic]: A Cross-Cultural Study. *International Journal of Rehabilitation Research*, 9, 355-362.

Rosaldo, M. (1974). Woman, Culture, and Society: A Theoretical Overview. In M. Rosaldo, & L. Lamphere (Eds.). *Women, Culture and Society: A Theoretical Overview*. Stanford, California: Stanford University Press.

Schilling, R.F., Kirkham, M.A., Snow, W.H., & Schinke, S.P. (1986). Single Mothers with Handicapped Children: Different from Their Married Counterparts? *Family Relations*, 35, 69-77.

Shin, M.Y. (1992). Immigrant and Racial Minority Women Organize. *Canadian Woman Studies*, 12, 55-57.

Shirley, O. (1983). *A Cry for Health: Poverty and Disability in the Third World*. Bath: Lonsdale Universal Printing Ltd.

Shurka, E., & Florian, V. (1983). A Study of Israeli Jewish and Arab Parental Perceptions of Their Disabled Children. *Journal of Comparative Family Studies*, XIV, 367-375.

Solberg, S. (1989). Women and Their Mental Health: A Reflection of Society's Expectations and Pressures? *Recent Advances in Nursing*, 25, 92-109.

Storhaug, K. (1983). Aspects of Living Conditions Among Groups of Disabled Children and Their Families in Norway: Family Situation, Mothers' Health, Financial Assistance. *Society, Science, and Medicine*, 17, 1837-1845.

Szekely, E.A. (1990). Immigrant Women and the Problem of Difference. In V. Dhruvarajan (Ed.). *Women and Well-Being/Les Femmes Et Le Mieux-Etre*. Montreal & Kingston: McGill-Queen's University Press.

Tekle-Haimanot, R., Abebe, M., Forsgren, L., Gebre-Mariam, A., Heijbel, J., Holmgren, G., & Ekstedt, J., (1991). Attitudes of Rural People in Central Ethiopia Toward Epilepsy. *Social Science and Medicine*, 32, 203-209.

Thomas, G. (1988). Women in the Greek Community of Nova Scotia. *Canadian Ethnic Studies*, XX, 84-93.

Thompson, T.L. (1984). A Comparison of Methods of Increasing Parental Consent Rates in Social Research. *Public Opinion Quarterly*, 48, 779-787.

Thorburn, M.J., & Marfo, K. (1990). *Practical Approaches to Childhood Disability in Developing Countries*. St. John's, Newfoundland: Project Seredec, Department of Educational Psychology, Memorial University of Newfoundland and Jamaica. West Indies: 3D Projects, Spanish Town.

Tonkinson, R. (1978). *The Mardudjara Aborigines: Living The Dream in Australia's Desert* . New York: Holt, Reinhart & Winston.

Trevino, B. (1991). Cultural Characteristics of Mexican Americans: Issues in Rehabilitation Counseling and Services. *Journal of Rehabilitation*, 57, 21-25.

Vaid, J. (1989). Seeking A Voice: South Asian Women's Groups in North America. In Asian Women United of California (Eds.). *Making Waves: An Anthology Of Writings By And About Asian American Women*. Boston: Beacon Press.

Warkany, J. (1977). Congenital Malformations in the Past. In T.V.N. Persaud, (Ed.). *Problems of Birth Defects*. Baltimore: University Park Press.

Weiss, S.J. (1991). Stressors Experienced by Family Caregivers of Children with Pervasive Developmental Disorders. *Child Psychiatry and Human Development*, 21, 203-217.

Westcott, H. (1991). The Abuse of Disabled Children: A Review of the Literature. *Child: care, health and development*, 17, 243-258.

Westermeyer, J. (1979). Folk concepts of Mental Disorder Among the Lao: Continuities with Similar Concepts in Other Cultures in Psychiatry. *Culture, Medicine and Psychiatry*, 3, 301-317.

Winzer, M., Rogow, S., & David, C. (1987). *Exceptional Children in Canada*. Scarborough, Ontario: Prentice-Hall Canada, Inc.

Yee, M. (1987). Chinese Canadian Women: Our Common Struggle. *Canadian Ethnic Studies*, 19, 174-184.

Ziolko, M.E. (1991). Counseling Parents of Children with Disabilities: A Review of the Literature and Implications for Practice. *Journal of Rehabilitation*, 57, 29-34.